'Eight months, three stone later and the medication didn't work anyway . . .'

Medication Issues in Counties Manukau Mental Health Services

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Executive Summary

Introduction

Medication is a key issue for both users and providers of mental health services. A recent admissions study (Abas, Vanderpyl et al. 2001), identified medication problems as a major reason for admission into the SAH acute psychiatric inpatient unit. This study examined stakeholder views of medication problems and their causes. A particular focus was on how stakeholders constructed the relationship between medication and recovery. Three areas were examined - (a) experiences with medication and mental health service delivery, and to identify beliefs, needs and expectations about medication from the perspective of multiple stakeholders. (b) issues in relationships and practices between stakeholders that formed barriers to good medication concordance management from the perspective of all stakeholders. And (c) how medication practices supported or impeded the development of recovery oriented service delivery.

Method

129 people participated in 19 stakeholder specific focus groups. Stakeholders included mental health service users and their family members, staff from hospital inpatient and community services, and staff from non-governmental community rehabilitation and accommodation providers

Results
Medication and Recovery

Perceptions of the relationship between taking medication and recovery were complex and contradictory. Medication was seen as critical to recovery, but also as a source of concern and fear.

- All stakeholders expressed ambivalence about medication in terms of, side effects, effectiveness, the trial and error approach to getting medications right for individuals, and fear of addiction.

- Demands for a broader approach to treatment planning, including the use of 'talking therapies' and alternative medicines, were common.

- Both internalised and external stigmatisation influenced people's views on taking medication.

All of the above influenced pathways in and out of taking medication. They were significant factors influencing medication concordance among stakeholders.

Cycles of blame

- Stakeholders identified many medication errors made by others

- Poor continuity of care and information were a major source of dissatisfaction

- Lack of resources, staff shortages and limited medication choices were key issues.

- Disagreements about medication treatment plans and implementation were common between
  …..all stakeholders

- Problems with getting disagreements and errors addressed were a common source of complaint by consumers, whanau and NGO staff.

- Failure to address errors and disagreements systematically resulted in mistrust and poor relations between stakeholders

- Stakeholder relationships were characterised by high levels of mistrust, dissatisfaction, and blaming of other services. They indicate a cycle of blame that forms many relationships between stakeholders.

Strategies for Change

1. Clinical services have a responsibility to organise regular multi-disciplinary reviews of a consumer's care, involving consumers, support workers, family, and carers
2. Where significant medication issues have been identified, a case conference should be called.
3. A standard for what constitutes a significant medication issue needs to be clarified
4. Examine current procedures for ensuring hand-over of information and care with staff changes is adequate and assesses level of disruption to care
5. Ensure quality guidelines are established and implemented to guide what information gets shared when staff change
6. Audit the quality of information sharing that occurs with staff changes.
7. Undertake annual anti-psychotic medication audits.
8. Key persons involved in the support and care of each consumer need to be identified and involvement negotiated as part of the initial assessment and ongoing management plan with the consumer.

The 'treatment team'

- There was a lack of clarity about who was involved in the treatment team. Roles and responsibilities of the different stakeholders, regarding medication treatment planning and implementation were vague and subject to debate amongst stakeholders.

- This resulted in problems with developing collaborative relationships across stakeholder groups.

- Stakeholders identified a need to build inclusive and collaborative relationships based on trust, rapport and good communication.

Strategies for Change

1. Audit occurrence of joint planning and sharing of documents between providers involved in a consumers care
2. Audit the quality of information sharing between SAH staff and NGO staff.
3. Continuity of SAH clinical staff associated with supported accommodation.
4. Implement more joint education sessions on medication between SAH staff and NGO staff
5. Clarify expectations and responsibilities for medication in the interface between non-governmental and hospital mental health service providers. Some of these could be addressed at the level of service contracts and the effectiveness of these relationships actively monitored by Counties Manukau DHB.

Information and education about medications

- Lack of knowledge about medication, diagnoses and treatment options was an issue for staff, consumers, families and carers.

- Another area of concern was effective delivery of education and information. Information delivery appeared ad hoc and inappropriately targeted to meet individual consumer and family needs. Education and information was frequently identified as a strategy for improvement.

Strategies for Change

1. All clinical services have a responsibility for knowing how to access up-to-date written/audio visual material on mental illness and medication treatments, and ensure that these resources are readily available to staff, families and consumers.

2. Information availability needs to be audited. Consumers and families need to be a part of the processes of auditing information availability in order to ensure that information meets their needs.

3. Evidence of information sharing with consumers and family needs to be provided in the case notes.

4. Some form of auditing and assessing of both the occurrence and the quality of information sharing needs to be implemented. Consumers and families must be involved in the evaluation of information sharing.

5. Collaboration between mental health services and drug companies to develop information packages about medications could be explored.

6. Identification of staff learning needs in the area of medication and diagnosis, and identification of treatment options

7. Assess and train staff to evaluate consumer and family knowledge about medication, knowledge of treatment options and diagnosis.

8. Development of staff skills to improve effective delivery of information and support consumers in making informed decisions.

9. Each team to have identified family and consumer representatives working alongside clinical staff to improve delivery of information.

10. Develop benchmarks to measure quality of delivery and provision of information about medications

11. Develop a regional database that identifies available information resources and training courses or materials on medication, treatment options and mental disorders, that identifies

Discussion

Medication treatment planning, implementation and monitoring presents a complex area in the delivery of recovery oriented mental health services. Numerous tensions and contradictions were identified in the relationship between medication, recovery and service responsiveness.

(a) A diversity of views raised about medication and its place in treatment of mental disorders amongst stakeholder groups.

(b) The relationship between coercion and medication treatment implementation is a major source of ambiguity for developing recovery oriented mental health services.

(c) Disagreements about medication treatment planning is common amongst stakeholder groups. There is a need to identify ways of addressing these disagreements in systematic ways that build collaborative relationships.

(d) Stakeholder relationships are structured by differences in knowledge, expertise and participation, as well as constructed through institutionalised status systems. These need to be addressed in any attempts to develop collaborative relations. The desire for collaborative relationships and involvement in the treatment team presents a major challenge to staff and consumers.

(e) Issues about resources emerged as a major factor affecting service delivery. Shortages of staff and vehicles and lack of adequate choices in medications resulted in crisis oriented service delivery.

(f) Education is argued to be a key aspect of empowerment. Simply increasing the information available will not address the issues. Attention needs to be paid both to how the information is delivered and to the quality and complexity of the information required.

The desire for collaborative relationships emerged as a dominant theme in all the focus groups. A key question is how can this occur in ways that acknowledge the complexity of responsibilities and major resource issues within Counties Manukau mental health services.

Limitations

- There was no attempt to quantify the results as is consistent with qualitative research

- Staff, family and consumer groups were organised through local organisations and were self-selected. Thus they may not be representative of a range of views.

- There was heavy reliance on notes from note takers in the focus as sessions were not tape-recorded.

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Introduction

Medication is a key issue for both users and providers of mental health services. A recent admissions study (Abas, Vanderpyl et al. 2001), identified medication issues as a major reason for admission into the acute inpatient psychiatric unit. This included admissions for reinstatement of medication (46%), relapse due to not taking medication as prescribed (35%) and misuse of medication and non-prescribed drugs (11%). Dimou (2000) highlights a complex range of factors that can affect medication taking:

- duration and complexity of therapy
- the degree of behavioural change that would be required
- side effects
- where and how medication is administered
- degree of contact with the clinician
- the consumer's family
- continuity of care
- satisfaction with services

Dimou shifts the focus to relationships of collaboration between tangata whai ora and clinician in the area of medication. In this way she begins to highlight key principles, that of recovery, empowerment and partnership. Collaboration implies that the tangata whai ora is an active participant, that he or she is presented with a range of options about treatment and given the opportunity to choose from among them (Jacobson and Greenley 2001). To have value, this relationship needs to take place in the context of recovery-oriented mental health services. 'Recovery' is defined as something that happens when people can live well in the presence or absence of their mental illness. This is recognised as being a different state for everyone. Recovery is not the same as cure; it is having more to life than illness. The health professional's role in recovery is to provide an environment where a person can be supported to manage their illness and its effects (Mental Health Commission 1998).

This project had three aims. First, to identify beliefs, needs and expectations about medication treatment from the perspective of multiple stakeholders (Non Governmental Support Services, inpatient and outpatient services, staff, families, and consumers). Second, to identify issues between stakeholders that form barriers to good medication management and concordance. Third, to explore how medication practices supported or impeded the development of recovery oriented service delivery. The results are based on the views gathered from nineteen stakeholder specific focus groups. The project was initiated by the Mental Health Commission (MHC) and developed as a joint project with Counties Manukau Mental Health Services.

It is important to keep in mind that the study was problem focused. Consequently, it does not examine the effective collaborative relationships that do exist within the Counties Manukau mental health services. What the study sought to do, was to understand how different stakeholders experienced issues with medication concordance. In addition, the study does not identify the 'truth' of the statements and issues identified in the focus groups. What it highlights is that disagreements occurred from the experiences of focus group participants.

Project Organisation

This project was initiated by the Mental Health Commission (MHC) and developed as a joint project with South Auckland Mental Health services. A steering group was formed comprising of representatives from all sectors involved in mental health services in Counties Manukau. This included representatives from various consumer organisations, Schizophrenia Fellowship, Non-governmental rehabilitation and residential providers, South Auckland Health and the Mental Health Commission, as well as the regional drug and alcohol service. The steering group met monthly for the duration of the project and was responsible for the direction of the project. See Figure one for a diagram of the project structure.

Four project subgroups were set up. A consumer subgroup met prior to each steering group meeting to develop recommendations to take to the steering group. In addition, there were three short-term subgroups made up of a mix of stakeholder representatives to develop and complete the information gathering phase of the project:

(1) The research design subgroup that designed the information-gathering phase and obtained ethics approval for the project.[1]

(2) The second subgroup undertook the recruitment of participants, organisation and facilitation of the focus groups.

(3) The third subgroup supported the data analysis process.

The Research and Audit in Mental Health Services team (REAMS) from South Auckland Health supported all phases of this project.

Terminology

There are several terms used in the literature in association with taking or not taking medication as prescribed. The term 'compliance' implies an authoritative relationship between clinician and consumer where the consumer follows the orders of their clinician. The use of the term non-compliance suggests that it is the consumer who is the problem if they don't take medication as prescribed. Similarly, 'adherence' refers to the extent to which consumers follow the instructions they are given for prescribed treatments. However, a successful regimen of taking medication needs to involve a collaborative relationship between consumer and clinician (Dimou 2000). The term 'concordance' is used in this study as it focuses attention on processes of negotiating an agreement about medication regimen between clinician and consumer (Kemp, Kirov et al. 1998).

Other terms used include the following:

Stakeholder: This term identifies individuals and organisations that are directly or indirectly involved in mental health services. In this study, seven stakeholder groups were represented at the project reference group level, the Mental Health Commission; service users and consumer organisation representatives; family representatives; non-governmental service providers; the regional drug and alcohol service and South Auckland Health Mental Health Service providers.

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[1] Project received ethical approval from the Auckland Ethics Committee of the Ministry of Health

Consumers: In order to identify this group we have used a mix of terms throughout the document, including consumers, service users and tangata whai ora. In the use of the term tangata whai ora we have drawn on the 'Guidelines for involving whanau and whanau of mental health consumers/tangata whai ora' to inform our understanding of this term. It refers to "the person who is the subject of care, assessment, and treatment processes in mental health. 'Tangata whai ora' means 'a person seeking health' – acknowledgements to Mason Durie" (Masters, Noseworthy et al. 2000: ii).

Whanau: Throughout the report we have used both whanau and family. These terms refer to family members of the consumer or the extended family/group of people who are important to the consumer. Family is not limited to relationships based on blood-ties or marriage.

A participatory action research model was utilised. Counties Manukau regional stakeholder representatives from service user organisations, whanau support services, non-governmental mental health community organisations (NGOs), and South Auckland Health clinical and management staff all supported the development of the project. Counties Manukau Mental Health Service users and their whanau and service providers participated in nineteen stakeholder-specific focus groups. Stakeholder representatives facilitated focus groups, eg consumers facilitated consumer focus groups. For the process of qualitative data analysis, a sub group of stakeholder representatives engaged in a critical review of the code development and the analysis developed by members of the research team. The data was analysed utilising a thematic analysis approach (Boyatzis 1998).

Results

About the Focus Group Participants

A total of 19 focus groups were conducted, including six SAH staff groups (n=39), six consumer groups (n=33), four NGO staff groups (n=22) and three family groups (n=35). The majority of participants were female, Pakeha and aged between 20-44 years.

Table 1 Demographic characteristics of focus group participants

	n	%
Gender		
Female	77	60.0%
Male	52	40.0%
Ethnicity		
Pakeha	72	57.6%
Maori	30	20.0%
Pacific Island	12	9.6%
Other	11	8.8%
Unknown (not stated)	4	3.0%
Age		
20-44 yrs	73	58.4%
45-64 yrs	45	36.0%
65+ yrs	7	5.6%
Unknown (not stated)	4	3.0%

The mean years of experience with the mental health system was very similar for three participant groups (consumers 15.8years, SAH staff 15.2years,or family 15.2years). It is interesting to note the

relatively shorter period of experience reported by the NGOs, this finding may be related to the comparatively recent development of community NGO services. (see Figure 1)

Figure 1: Mean number of years experience with the mental health system for each participant group
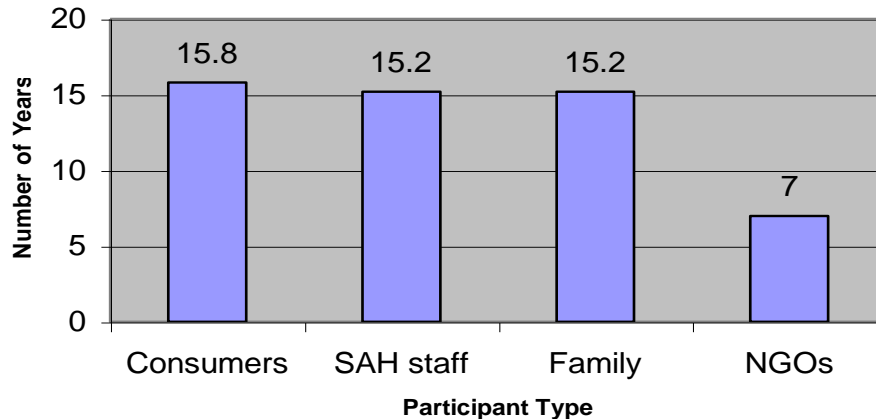
(a) Medication and Recovery

Many participants described medication as crucial in the reduction of symptoms and enabling feelings of well-being. Not taking medications was linked with relapse.

> *Medication is a part of my lifestyle. If I don't take it I am up until 2 am. I can't function that way (Consumer)*
>
> *Without medications I am suicidal. I take it hoping that these help me improve. It stops me feeling actively suicidal. (Consumer)*
>
> *I agree with medications. If I wasn't on it, I would get imaginitus (sic) or hallucinations. I'd be psychotic (Consumer)*

Taking medication was a first step in the process of recovery. For many tangata whai ora, coming to terms with taking medication centred on finding an acceptable balance between effectiveness, minimal side effects and developing a good quality of life. Doctors felt that without medication tangata whai ora would have fewer treatment choices, increased hospitalisations and increased safety issues.

All stakeholder groups expressed ambivalence about medication. A common expression identified medication as a *'necessary evil'*. Medication was described as both helpful and damaging at the same time, especially with regard to the numerous side effects. Many consumers and whanau feared addiction and dependency on medication. Another area of ambivalence was the unknown effects of long-term use of medications. Doctors outlined a need to have open dialogue about benefits and drawbacks of medication. They identified the need for constant review of available medications to find the best treatment with the least side effects. Ambivalence was expressed about this regime of open discussion about side effects. On the one hand consumers and whanau felt a need to be fully informed and on the other hand whanau and staff feared that knowing all about the possible side effects might discourage people from accepting medication.

In addition, there was a criticism of the narrow range of treatment options dominating service delivery. Consumers, their families and some NGO staff were critical of the tendency to use medication as the only form of treatment. Counselling therapies emerged as a common alternative treatment, either on its own or in conjunction with medication. A range of alternatives were suggested alongside the use of anti-psychotic medications, such as karakia, massage, tohunga or herbal remedies.

Ambivalence about medication was influenced by the stigma of mental illness and issues around wanting to be "normal" but feeling "different" as a person taking medication. Staff, whanau and tangata whai ora identified a need to resolve issues of internalised shame and stigma associated with having a mental illness. This involved a process of shifting from viewing illness through a lens of stigma to acceptance of illness.

The above issues were associated with many of the pathways in and out of taking medication. The most common pathway involved stopping taking medication because one was feeling well. Other pathways to and from taking medication included:

- spirituality or belief systems that either encourage or discourage consumers to take medication;

- insight into the need for medication, versus denial;

- some consumers only took medication if they were coerced to do so, but for others, coercion lead then to stop taking it as a means of regaining some control.

Doctors reported searching to understand reasons for the pathways in and out of taking medication. They noted a contemporary trend of doctors emphasising tangata whai ora options in the area of medications. Also, they reiterated the need to explore why people decided to stop taking medication because there could be a number of reasons why people would stop taking them. They identified a feeling of frustration when consumers relapsed again and again due to not taking medication. At the same time, they acknowledge the need to use the Mental Health Act to enforce medication taking for some consumers in order to support their recovery. Taking medications was also very much influenced by situational factors.

> *Finding out why the patient doesn't take their medication, always a difficulty and a dilemma for psychiatrists. There is a whole range of reasons why people stop taking their medications e.g. many have beliefs about medications i.e. they believe they are damaging or some might forget etc. Can be very upsetting and challenging when people come back time and time again because they've stopped taking their medication. (SAH-Doctors)*

> *If patient meets the criteria under the Mental Health Act to be sectioned and is not taking their medication, sometimes the doctor may be compelled to use the Act to ensure they take medications. (SAH-Doctors)*

> *If someone is working hard not to take medications, it is difficult to help them. Needs to be part of a holistic team approach. (SAH-Doctors)*

The views on medication taking described above suggest how individual decisions about medication take place in a social context influenced by their histories, cultures and relationships with others (eg service providers, such as doctors, key workers, as well as families and friends). Recovery is not just about getting medication right but also a process of ongoing dialogue, information sharing and negotiation between tangata whai ora, whanau and staff to address the complexity and ambivalence associated with taking medications for severe mental illness.

(b) The 'treatment team'

Medication management involves many different individuals and services from when the consumer first presents to a mental health service to the point at which a consumer takes medication. The primary relationship was usually described in terms of the doctor diagnosing and prescribing with the consumer taking medication. Secondary to this relationship were others such as the pharmacist, family, key worker or community support worker who were involved in a more perfunctory role of giving medication or of encouraging medication taking. Medication management was mostly conceptualised as a hierarchy of authority and responsibility where doctors were at the pinnacle of this hierarchy, with each stakeholder group below the doctors experiencing increasing levels of powerlessness.[2] Stakeholders struggled to sort through how to address disagreements about treatment regimes. They also indicated areas of ambivalence, and/or ineffectiveness in challenging treatment plans.

Figure 2: A hierarchy of relationships in medication management
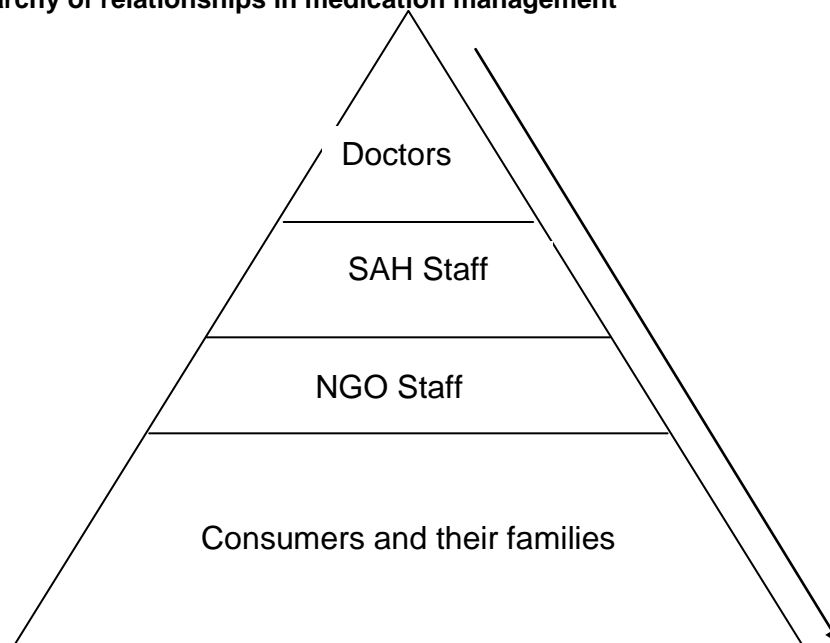
Consumers, whanau and staff experienced service provision as coming from isolated teams based around specific services (eg clinical teams, community support workers), rather than seamless process of service delivery. All groups expressed a desire for participation in a collaborative inclusive treatment team. Clinical staff assumed NGO staff should support consumers to take medications and call clinical staff if there were 'serious' or 'real' problems. NGO staff felt they should be treated as part of the treatment team, as did the family members because they had a closer relationship with the tangata whai ora. The role of the family was linked to supporting the tangata whai ora to take medication as prescribed. Consumers focussed on the need for clinical staff to get prescribing medication right, monitor how well the medication was working and support consumers to take medication when they were unwell.

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[2] Occasionally, PHARMAC was identified as being at the pinnacle of this hierarchy in controlling the subsidised drugs available in New Zealand

What emerged from the discussions were experiences of dissatisfaction, exclusion and marginalisation. Participants described experiences of us/them divisions, talking past each other and feelings of not being heard.

> The psychiatrist didn't listen to me. I wanted to cut down my medication and I have been saying that to the psychiatrist from the last couple of visits, but nothing happens. I wanted to stop taking my medication, but I didn't have the expertise of the psychiatrist. But the psychiatrist is not going to listen. (Consumer)

> There are confusing messages sometimes. Supported houses do not administer medication if consumer uses alcohol, but they do not always manage to stop access to these drugs. Yet the doctor says take the medication even if he has had some alcohol, but the staff at the home won't accept this and will always withhold the medications, even for a small amount of alcohol, and then our son just deteriorates. (Family)

Families criticised staff for not listening to them. *'Family input is extremely important. Yet we didn't feel listened to or have our comments acted on'* (Family). *'Too many clinicians, they do not get to know the client or ask the family'* (Family). NGO staff were criticised for not taking appropriate actions and responsibilities by SAH clinical staff. NGO staff and families frequently felt excluded and marginalised from treatment planning. Whilst consumers tended to be constructed as recipients of services, albeit resisting ones at times. Participants described a lack of clarity about where NGO responsibility ended and SAH clinical staff responsibility began, of who was responsible for consumers taking medications, or for addressing issues with prescribing. *'Clients have a cocktail of medications of many different tablets, and dependency on PRN. You need a plan with clinicians. Some consumers are ignorant. Sometimes they don't come and listen. They don't comply with medications. Who is responsible?'* (NGO). *The clinical team assessed the client, moderated their mediation and then changed the medication again. This has led to a cycle of overmedication, in which the person became a zombie, then to less medication, then it is back to square one and the cycle restarts. As Community Support Workers it is out of our hands. We are just there to catch clients when they fall* (NGO). If a consumer refused to take medication, NGO staff felt powerless to ensure the medication was taken and ultimately saw the enforcement of medication taking as belonging with the SAH keyworker.

Another major role issue, for NGOs in particular, was a sense of being powerless in the context of a consumer's treatment process, yet being responsible for consumers as they are the people who have regular contact with them, and having to *"pick up the pieces"* if anything goes wrong. Families also reported similar issues of being *"powerless yet responsible"*. NGO staff described how on one hand there was a sense that they did not have sufficient medication knowledge and they were often in a position that they did not know how to deal with medication problems. On the other hand they had significant knowledge of consumers and their treatment process, but that this knowledge was not valued because they were not "experts". *Some clinical staff don't give credit to the CSW workers, they don't give us credit for having knowledge around various issues. We are seen as having a lack of status and lacking in expertise* (NGO). The issue is not who is included in the treatment team, but when and how different stakeholder groups are included in the treatment team. However, references made to a wider treatment team tended to lack clarity about who should be involved when, and the roles and responsibilities of each stakeholder group. This presented as a major source of ambiguity and resentment for whanau and NGO support staff in their relationships with clinical staff.

Staff, tangata whai ora and whanau within mental health services experienced a contradiction between being a supporter and enforcer of medication taking. This appeared to be a contributing factor to the ambiguity and tensions identified above. Staff and NGOs both see themselves as

advocates and support people for the tangata whai ora, but may be in a situation of trying to persuade tangata whai ora to take medication. NGO and SAH staff described tension in terms of feeling uncomfortable with various aspects of their roles and sorting out boundaries between client-staff, and friend relationships. NGO staff said they were not being happy about having to take on a policing role with clients, feeling that it is an "*intrusion'* or "*imposition*" for them to do so. Family members expressed similar tension regarding their roles as being supporters of their family member but feeling like they had to enforce medication taking. They expressed a great deal of anxiety over crossing a perceived boundary from supporter of their family member to collaborator with staff. These tensions highlight a major contradiction in attempts to develop collaborative treatment teams.

Evident in the doctors' focus group was struggles over defining roles and responsibilities in the area of medication, along with ways of improving collaboration across the different groups. As they identified, while everyone else did have some responsibility in the area of medication, ultimately, doctors had to take responsibility for medication decisions. They spoke of the struggles to fulfil their role in the light of high caseloads, frequent changes in staff and lack of resources. At the same time there was an emphasis on involving others in the process of monitoring. As a result, doctors suggested that much of the monitoring role had shifted to key workers, as well as other stakeholders. However, this appeared to happen by default rather than careful planning.

> *Keyworkers have almost become the primary person who has responsibility for monitoring medications, effectiveness of medications, side effect and relapse. Doctors depend on keyworkers to do this and also on the families. Keyworkers are not necessarily trained in nursing or have any knowledge of psychiatric medication. They may have a good role in psychosocial skills e.g. they may be trained as a social worker, but they have limited skill knowledge base in their roles around medication – this can be problematic, as keyworkers need to monitor things like, did the patient get their blister pack? (SAH – Doctors)*
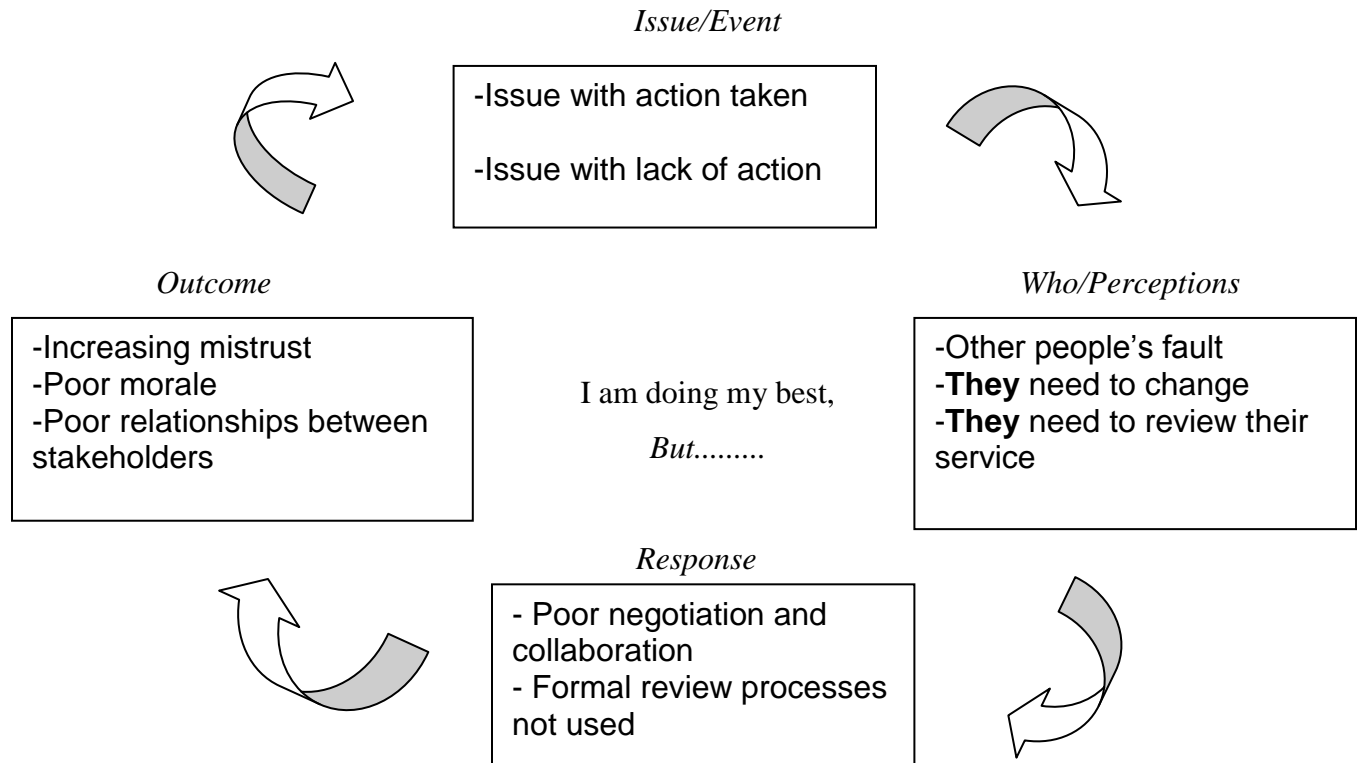
From the view of consumers, whanau and NGO staff, the treatment team remains hierarchical with the doctor being in control of medication prescribing and others complying or supporting compliance. They saw little opportunity to influence the decision making process and little responsiveness to disagreement about medication treatment plans. The main concern was the lack of collaboration in addressing disagreement and a lack of real inclusion of consumers, families and NGO staff in the treatment planning team. Not being listened to was a common concern. Families and NGOs felt sandwiched between the clinical team and the consumer, powerless and their role undervalued. The lack of agreement over roles and responsibilities contributed to ambiguity and anxiety amongst stakeholders.

(c) Cycles of blame

The focus groups identified a large number of errors, problems and disagreements between stakeholders. Three common areas emerged; (a) mistakes in prescribing medication, (b) poor continuity of care and information, and (c) consumers and families not supporting doctor decisions about medication treatment. Although some staff were identified as being excellent, other staff were perceived to be not very good at their jobs. Each group felt they were doing their best but that other stakeholders caused problems, by not fulfilling their role or doing their job properly. It was usually other people who had to change or improve their services. Focus group participants frequently described processes in which they felt no appropriate action had been taken following errors or disagreements. Each incident was part of a whole series of issues that were not addressed amongst stakeholders and contributed to poor relations. Two issues were common in this cycle of blame, first,

an experience of hopelessness and futility in getting issues addressed, and second, the problem was seen as someone else's fault

Figure 3: A cycle of blame

Issue/Event

-Issue with action taken

-Issue with lack of action

Outcome

-Increasing mistrust
-Poor morale
-Poor relationships between stakeholders

I am doing my best,

But.........

Who/Perceptions

-Other people's fault
-**They** need to change
-**They** need to review their service

Response

- Poor negotiation and collaboration
- Formal review processes not used

Common issues involved over and under medicating consumers, or prescribing the wrong drugs and taking a long time to fix mistakes.

> *The crisis team will give more medication, when someone was being overmedicated already. (Consumer)*
>
> *Treating everyone the same in hospital, there is a tendency to overmedicate. (Family)*
>
> *Sometimes the diagnosis is not always correct so obviously the medication won't be correct. (SAH)*

Another problem area involved giving medications that just don't work from a consumer perspective, incorrect numbers of pills in the blister packs, changes in the number, size or colour of the pills with each prescription, or having drugs prescribed that shouldn't go together according to the information given with the medication. Lack of timely review and or poor assessment processes by clinicians emerged as another issue.

> *Sometimes information that comes with the medication identifies which drugs should not go together. I had a situation where the doctor was prescribing me two drugs which the information on the drug package said should not go together. (Consumer)*
>
> *It took the doctor eight months and three stones later to change me to another drug from something that wasn't working anyway. (Consumer)*
>
> *At times the medication used to treat side effects is used indiscriminately. There is no real attempt to assess whether or not there were actually side effects and instead just simply prescribe this treatment. (SAH)*

Some of the consumers are not willing to take medications and there are repercussions for not taking it. But this is not helped by the infrequent reviews by clinicians. (NGO)

I was told by the psychiatrist to come off my medication because of the long-term side effects. I tried to but I had terrible withdrawals. I should have been given a substitute while coming off the medication and been closely monitored, but they didn't do that. I was told this but nothing has been done and I have not seen a keyworker for ages. (Consumer)

I had frequent rescheduling of appointments, The psychiatrist prescribed the wrong drugs at really high doses. For a long time I was having really bad side effects to the point of having seizures, migraines, shaking. Part of this was the result of getting really addicted to the medications that I was on. I went to the Community Mental Health Centre and received no help at all. I had a real sense of neglect by the psychiatrist. (Consumer)

Thus medication problems were not just linked to one area, but to diagnosis, dosages, administration, appropriate use of medications and review/monitoring and assessment. Lack of continuity of care was a major issue for all stakeholders. Key areas in which lack of continuity was identified involved the transitions between services for consumers and frequent changes of doctors and key-workers. *I have been left on medications that were not working and the psychiatrist who prescribed them had left, and then the new psychiatrist wouldn't change the medications even though I had talked to them again and again* (Consumer). A common source of complaint was the six month rotation of registrars. This was exacerbated by poor processes in the transition of care from old to new staff. Issues involved: (a) The doctor changing a medication regime that was believed to be working with poor outcomes for the consumer. *'The client was on medications for years and doing well. Then all of a sudden the new doctor changed the medications and the client became unwell. She asked to be put back on the old medications, but she was never listened to'* (NGO). (b) Service users having to repeat their stories every time staff changed. (c) Poor documentation and charting. *'There is an issue with charts not being current. When a doctor is away, the crisis worker or key worker need to have the correct information on the charts'* (SAH). These issues point to poorly managed transitions in passing of information and inconsistency in agreement about treatment plans among old and new staff. They contribute to poor continuity of care.

There was a mixture of views on family and tangata whai ora actions and responsibilities in the area of medication. Both NGO and SAH staff tended to blame families and consumers for not taking medications, construe consumers that did not take their medication as irresponsible, or devious. At the same time stakeholders supporting consumers in managing medication regimes reported experiencing feelings of powerless and guilt in the face of tangata whai ora refusal to take medication. Situations where consumers did not take medication as prescribed tended to be seen as a negative act of resistance or negative practice of power, eg lack of insight and lack of knowledge. There was an assumption of irresponsibility and ignorance of those who failed to follow or support the prescribed medication regimes. Blaming of tangata whai ora and whanau was mixed with arguments about consumer self-responsibility, the need to recognise consumer knowledge and choice. Addressing practices that inadvertently maintain dependence on the service, rather than promoting autonomy and consumer responsibility for the choices were identified as a key tension in service delivery.

Lack of resources was frequently blamed for issues in the areas of service delivery and medication treatments. This included shortage of staff, lack of adequate resources and experienced staff. These were felt to be a major cause of many of the problems discussed previously. PHARMAC was often blamed for the lack of availability of superior medications, for the lack of subsidies and high costs of

some medications. Stakeholders described how sometimes an inferior drug was prescribed because the better drugs were not available in New Zealand.

The number of errors, poor continuity of care, and blame culture between the different stakeholder groups highlights significant tensions affecting management of medication across stakeholder groups. What stands out is the overwhelming focus on clinical staff errors in the areas of diagnosis, prescribing and delays in reviews or failure to monitor the effects of medications. Many staff reported differing views about the ability of whanau and consumers to take or support prescribed medication regimes. Within this cycle of blame, there are poorly addressed issues resulting in increasing levels of mistrust between stakeholders. Each issue that is not addressed appeared to compound the lack of trust and poor stakeholder relationships, culminating in a sense of futility and hopelessness. It suggests a lack of systematic review of practices and relationships across services. The lack of resources, including staff shortages, expense of medication and lack of medication choices available in New Zealand were identified as contributing to poor medication practices by stakeholders.

(d) Information and education about medications

All stakeholder groups expressed a desire for more information in the area of medication, diagnosis and treatment options. Many consumers expressed a desire to have a better understanding of the nature and course of their diagnoses and of how medication actually worked. Lack of information affected some consumers because they did not understand why they needed medication. Access to more information was linked to a greater level of control and making informed decisions. Consumer and family participants felt powerless and scared when they didn't understand what was happening to them. *'They didn't tell us what to expect and the first dystonic reaction was very scary'*(Family). *When I first went into hospital, there was no explanation why I had to take all the medications they gave me. Instead of giving me the box and saying, read the information, I wanted someone to go through it with me* (Consumer).

SAH and NGO staff also desired increased access to information about medication. Staff expressed a need for more education about medication to enable them to feel more comfortable, knowledgeable and competent in the role of educator. There are no formal courses or in-service training available to SAH staff or NGO staff on medication. Staff receive information about medication from experienced peers, drug company presentations and publications, by consulting the mental health specialist pharmacist, and the New Ethical publication and web site. NGO staff have even fewer educational resources about medication available to them.

Although many focus group participants identified a lack of information, numerous sources of information were also cited in the focus groups. Accessing information and knowing about it appeared to be a major problem. It appeared almost accidental to receive information rather than a central part of medication management planning dependent on the good luck of having an informed key worker, or the good fortune of knowing who to ask and what to ask for. Consumers expressed a need for different levels of information in terms of depth and complexity. For example, some participants asked for more technical information on what is happening and how the medication will affect the disorder, eg to describe in more detail what is actually happening to the brain when unwell. Others reported that too much information was overwhelming. Some people found the

written material too complex for their needs, others wanted a high level of complexity and felt patronised by being offered superficial explanations.

The access to and delivery of information was a key issue for all the focus groups and highlights a lack of consistency in information received by stakeholders. Tangata whai ora and whanau described struggling to find appropriate information at the quality and level they needed. At the same time, staff reported feeling ill-prepared to deliver information and education about medication.

Discussion: Barriers to medication practices supporting recovery oriented service delivery

The information gathered for this project was derived from focus groups. The approach taken meant participants are able to explore and clarify their views in ways that are often less available in one-to-one interviews or questionnaires. However, there were a number of limitations in the interpretation and conclusions drawn from the focus group information. Although participants were encouraged to report all their responses, this did not always occur. Thus it was not possible to assess how common any particular viewpoint was within any one focus group. Analysis involved identifying common issues and understandings of medication across the focus groups. There was no attempt to quantify the information. In utilising a structured interviewing approach, groups differed in skill and experience of moving from brainstorm to theming. Consequently, there was significant variability in the quality of theming between focus groups. As the focus groups were not taped, we relied on the note taker and the short hand responses written by the co-facilitator. This brings increasing risk of mis-representation of participant comments. Attempts to address this involved checking the accuracy of what was written by writing responses on the large pieces of paper visible to all participants during the focus group. In addition, staff, family and consumer groups were organised through local organisations and were self-selected. Thus they may not be representative of the full range of views present in each of the stakeholder groups.

The Participatory Action Research (PAR) approach was integral to this project. PAR has three interrelated cycles, (1) education and analysis cycle, (2) investigation and (3) an action stage – a 'look, think, act' spiral. PAR is characterised by facilitating involvement of stakeholder groups and on achieving political parity in decisions making processes, along with a commitment to consensual and informed joint construction of the project. It involved a participatory and consensual approach towards investigating problems and developing plans to deal with them. This influenced the decision to utilise focus groups for they supported extensive participation by those who worked in and utilised mental health services within the Counties Manukau area. This report presents an incomplete PAR cycle in terms of the larger project goal of implementing improvements based on this 'look, think, act' spiral, a report of the focus groups is appropriate at this stage. Within the PAR cycle, the first act stage has yet to be fully implemented. To this end, a day-long workshop brought all the focus group participants into the look, think, act loop of PAR late last year. At this workshop summaries of the focus group information was presented and participants developed action plans. This was conceived as an integral part of a process in which participants are empowered to act on their own behalf as active participants in change. A stakeholder reference group for the project also met again early in the year, to develop the next steps. It is these next steps that need to be implemented.

(a) The place of medication in recovery

The focus groups highlighted a complex and contradictory relationship between taking medications and recovery. In the focus groups there was recognition of ways in which medication could contribute to a state of wellness, and as a step in the road to autonomy, empowerment and community integration. However fears about addiction, appalling experiences of side effects, long processes of trial and error in finding effective medications, and issues of stigmatisation all contributed to experiences of fear, ambivalence and mistrust of medications. Issues were raised about the lack of choices and consideration given to alternative forms of treatment in treatment plans. These views on medication were influential in consumer decisions to take or not take medication.

Mead and Copeland (2000) outline how recovery involves the following consumer rights in the area of medication:

- Making life and treatment choices for themselves
- Building their own crisis and treatment plans . . .
- Accessing information around medication side effects
- Refusing any treatment (particularly those that are potentially hazardous)

Although many people feel that medications are helpful in reducing the most difficult symptoms, the notion that medication is the only rational options for reducing psychiatric symptoms was being challenged by many consumers. Mead and Copeland (2000) describe how in the recovery scenario, medication is one of many options and choices for reducing symptoms. They identify a range of other skills, strategies and techniques to address symptoms. They go on to outline how the views of clinicians and consumers may increasingly differ around the role of medications in ways that are not explored by clinicians with consumers

> *When people who have shared similar experiences get together, they begin to talk about their concerns about medications and alternatives that could be helpful. They build up a kind of group empowerment that begins to challenge the notion of medications as the only way to address their symptoms. Many physicians, on the other hand, worry that stopping the medication will worsen symptoms.(Mead and Copeland 2000, p 324)*

Not only does this highlight the potential for conflicting views about medication between clinician and consumer, but it also becomes part of a polarisation of views and potentially an amplification of hierarchical relationships between clinicians and consumers.

> *People feel that if they question their doctors about decreasing or getting off medications, they will be threatened with involuntary hospitalization or treatment. Doctors fear that people are jumping on an unreliable bandwagon that may lead to severe symptoms and jeopardise the person's safety. Consequently, talk about medication often goes on without counsel with doctors. (Mead and Copeland 2000, p324)*

Even while doctors emphasised open dialogue, others may resist this because of how relations between users and providers are structured as a hierarchy. Mead and Copeland (2000) put the emphasis on exploration of choice and self-responsibility around medications. They argue for a need to develop dialogue about symptoms so that individuals can make informed choices. This involves ensuring that planning and treatment is a truly collaborative process with personal choice as the bottom line. They also address the issue of situations where symptoms become so severe for individuals that they become a danger to themselves and/or to others. The use of personal crisis plans that tell close supporters when they need to step in and take over responsibility for that person's care is recommended (Mead and Copeland 2000). Jacobson and Curtis (2000, p 337) also argue that this sort of planning can mitigate the 'negative consequences of crisis situations and

diminish the use of coercive interventions such as an involuntary commitment and . . . forced medication.'

A report examining views on clinical accountability in New Zealand mental health services identifies the following key tensions and argue for a need for increasing sophistication in thinking and shared models that recognise and address 'the importance of consumer choice, participation in decision-making processes, and empowerment as aspects of ethical and accountable practice' (Chiplin, Bos et al. 1998: 15). Key questions become: 'Does consumer choice always supercede other considerations? At what point is individual choice superceded by prevailing community standards and the need for social regulation? What is the responsibility of the mental health system when consumer choice results in tangible reduction in safety for the consumer or the community? How is consumer preference reconciled with conflicting family needs?' (Chiplin, Bos et al. 1998: 15). A major limitation in this project is the failure to explore the use of coercion or compulsory treatment orders to support medication adherence. We were interested to see if this would emerge as an issue within the focus groups. It rarely emerged as a major issue. This may also be a consequence of consumer focus group participant selection procedures. At the same time vague references to tensions by staff and family about their roles suggest coercion is an issue. The infrequent references to the use of compulsory treatment orders or vulnerability to coercion in the relationship makes it difficult to explore this issue. The literature on recovery identifies the very significant contradictions between espousing a recovery orientation and use of compulsory treatment regimes. This is a subject that warrants further investigation.

There is a growing body of evidence that shows that the selective use of community treatment orders can improve community tenure and health outcomes. A randomised controlled trial in North Carolina aimed to look at the effectiveness of outpatient commitment by randomly assigning patients who had had involuntary hospitalisation, to be committed to involuntary outpatient treatment, or to be released from compulsory status (Swartz, Swanson et al. 1999). People with non-affective psychotic disorders preferentially benefited from longer periods of outpatient commitment, reducing hospital admissions by 72%. Associated research with this study looked at the effect of involuntary outpatient commitment on people with severe mental illness (Swanson, Swartz et al. 2000). The study found that with commitment of more than six months to regular outpatient services, more than three per month had a reduced rate of substance abuse and increased compliance with medication. Consumers who are acutely unwell and do not engage with services are at risk of drifting into either homelessness or become criminalised within the justice system. These studies suggest that the use of community treatment orders combined with assertive follow up can support consumers' right to treatment. The tension that needs exploring is how can a mental health system maintain a recovery focus and maintain service user autonomy and control in situations of crisis.

(b) Enhancing medication treatment planning, implementation and review

Errors and disagreements in an area as complex as psychiatric medication are to be expected. Yet what emerges from these focus groups is a failure to systematically address the errors and disagreements with regard to the treatment regime amongst stakeholder groups. This relates to failing to develop collaborative relationships in the process of treatment planning, implementation and monitoring. The two issues are intimately entwined in that systematically developing collaborative relationships will potentially address many errors and disagreements raised by the various stakeholders.

Errors, disagreement about medication treatment regimes, poor continuity of care and lack of information were common sources of dissatisfaction amongst the focus group participants. Within the focus groups, there was much blaming other stakeholders for problems and errors. This was linked to issues of mistrust and poor relations between stakeholders. The stakeholder groups identified different 'blame' issues. Consumers experienced feeling neglected and that information was withheld from them. Family members talked about similar issues regarding neglect, and in addition referred often to being excluded from the treatment team and issues with getting disagreement about treatment addressed. NGO staff also expressed a lot of dissatisfaction with their experiences of being frequently excluded or marginalised from the treatment team. SAH and NGO staff tended to talk about feeling devalued in their roles, and also expressed mistrust of consumers and family members in some circumstances.

It is the clinician-consumer relationship that emerges as primary in any medication treatment regime. There has been a major shift in this relationship from a paternalistic one of 'doctor knows best, the consumer passively takes the medication' to one in which doctors and consumers are constructed as active collaborators in developing treatment plans. A fundamental shift from 'doing to or for others' to 'working with others' in the delivery of services was part of the discussion about medication treatment planning in the focus groups. This is consistent with much of the literature on treatment regimes and recovery. Current literature on issues related to medication adherence pay a lot of attention to the development of collaborative partnerships between clinician and consumer (Dimou 2000). What this literature appears to miss is the involvement of multiple people such as family, NGO support workers, pharmacist, and general practitioners in treatment planning, implementation and monitoring. Practices of exclusion and marginalisation of these groups emerged as the major issue in many of the focus groups.

The development of collaborative ways of working and of partnership has been identified as an important aspect of recovery-oriented service delivery (Jacobson and Greenley 2001). In fact, the Community Liaison Committee of the Royal Australian and New Zealand College of Psychiatrists outline a model of partnership in their *'Guidelines for involving families and whanau of mental health consumer/tangata whai ora in care, assessment and treatment processes'* that has relevance for this discussion. They outline the following as the basis for effective working relationships:

- Consultation
- Co-operation
- Mutual respect
- Equality
- Sharing of complementary resources and skills
- Clarity of expectations (Masters, Noseworthy et al. 2000)

They emphasise how developing partnerships is not so much as event as an ongoing process focused on relationship building. However, questions about accountability and processes for addressing issues, disagreements, and experiences of powerlessness and exclusion remain weak in this model. Assumptions about the desirability and possibility of equality between all participants underpins this model. Although a desire to create collaborative relationships based on equality between all participants is a good first step, there is also a need critically to explore how power, and its consequences for equality, is played out in these relationships. Significant differences in knowledge, histories of deprivation and marginalisation, institutionalised status hierarchies, different levels of participation all influence the development of collaborative relationships based on co-operation,

mutual respect and equality. Defining the 'treatment team' in ways that enable equality in participation by all relevant stakeholders is complicated by many factors unique to each situation. Thus rather than an elusive goal of equality, it may be more useful to specify in advance who will be a part of the treatment team, when they will be involved and in what ways. This needs to occur through processes of negotiation with the consumer in ways that acknowledge and challenge sources of differences in power, eg knowledge, expertise and institutional status hierarchies.

Within the focus groups, the doctors received a disproportionate amount of criticism. This may be a reflection of the research model used in that the overwhelming focus is on hearing previously marginalised voices. However, in this process there is often a tendency for those more 'powerful' voices to be rendered invisible or marginalised. This is part of the politics of research within and between organisations. The criticisms levelled at doctors both reflects historical patterns of doctor-patient relationships, and a tendency to blame individuals when working within systems under pressure, rather than seeing the issues as part of a broader inequitable system. At the same time, the focus groups described the very real frustration associated with errors, disagreements about medication treatments and poor documentation practices by doctors. Thus it becomes a question about how doctors as a group can address some of the systematic issues in collaboration with other stakeholders whilst addressing some of the individual errors and disagreements.

(c) Education, Empowerment, Collaboration.

The participants identified education/information as a key component of medication management. Many of the participants expressed the desire to have a better understanding of how medication actually worked and ongoing education to expand their knowledge and involvement in their medication management. This supports Kelly and Scott (1990) who found that consumers and whanau need and want more information on the nature, aetiology and treatment of illness than they are currently receiving from clinicians. Many responses were general, ie. just noting a lack of information or saying more education was needed. But some consumers and whanau expressed considerable mistrust of clinical staff across various contexts. This centred on feeling that staff do not trust them and withhold information or even lie to them to gain their complicity. Education was seen as important as an ongoing process at the beginning of medication treatment, at different stages throughout the process and needing frequent repetition. Kelly and Scott (1990) support the importance frequent repetition of information as a critical ingredient of patient education. It was felt that as mental state improved more comprehensive information could be offered. Consumers can best be involved from a well-informed position.

Simply increasing knowledge will not improve collaboration between clinician and consumer. There is the risk that education will be perceived by clinicians as a one way street, that is, convince the patient but make no alteration to the benign paternalistic attitude of the clinician. Melamed and Szor (1999) suggest that one of the main reasons for non-adherence lies within the clinician/consumer relationship. Consumers need to feel in control of their treatment by being offered information and different options. Concordance is based on a type of contract between two people and the outcome is dependent on the involvement and education of both consumer and clinician (Dimou 2000). It is emphasised that merely increasing consumer education both in quality and quantity will not necessarily have a positive effect on medication adherence. The building of a consumer/clinician relationship is an equally important indicator of success. Dimou (2000) suggests there is a need to have an organised plan, which includes both consumer and clinician education and an accurate

assessment of consumer knowledge about their medication. Consumers need to be seen as active participants, not passive recipients, and staff to recognise the consumer as a valuable resource in their own care (Dimou 2000). It is also important to recognise the diversity of perspectives regarding links between taking or not taking medication and recovery, and the fact that non-adherence might arise from a rational decision on the part of the consumer as opposed to always being an error. For example, a consumer choice not to take medication may arise from a rational decision and there is a need for clinicians to accept this possibility and not assume that they "know best".

In conclusion, what stands out is the desire in the focus groups for the development of collaborative relationships across stakeholders. A key question becomes how this can be developed. As the focus groups indicate medication management is affected by a dominant pattern of blaming others and disagreement across groups, issues in terms of lack of information and education about medication, along with resource constraints within Counties Manukau Mental Health Services. At the same time medication management needs to occur in ways that address the complexity of service responsibilities within the context of consumer choices and rights. Medication planning, implementation and review presents service providers with a major challenge in the delivery of recovery oriented services.

Recommendations

The following recommendations are based on the focus group results and the day-long workshop exploring strategies to address medication issues attended by many of the focus group participants. National Mental Health Standards relevant to each of the areas of concern have been identified. Many of the recommendations are focused on improving quality monitoring of services, addressing issues over clinical, consumer and family accountabilities, along with the identification of gaps in service delivery. Shifting from a culture of blame to one of collaboration will require a process of working proactively to improve systems of accountability between staff and service users across services.

1.	**Collaborative Relationships between Clinical Staff, consumers, family and carers**
1.1	**Issues identified**

    1.1.1. Issues with developing collaborative medication treatment planning, implementation and review processes.

    1.1.2. Poorly managed medication changes

    1.1.3. Lack of timely review of medication treatments

    1.1.4. Poorly managed transitions and sharing of information with changes of doctor and key workers

1.2 **Relevant National Mental Health Standards**

Standard Six: Safety (6.2)

Treatment and support offered by the mental health service will strive to protect the consumer from all forms of neglect, abuse and exploitation

Standard 14 Entry

The mental health service establishes clear lines of communication within the service . . . , to minimise duplicating collection of consumer data.

Standard 15 Consumer assessment (15.13)

All active consumers, whether voluntary or involuntary, are reviewed at least every four weeks. The review should be multi-disciplinary, conducted with peers and more experienced colleagues, and recorded in the individual clinical record.

Standard 15 Consumer assessment (15.14)

A review of a consumer is additionally conducted when: the consumer requests a review, . . . the consumer declines treatment and support, . . . or monitoring of consumer outcomes indicate a sustained decline

Standard 16 Quality Care and Treatment (16.9)

The treatment and support provided by the mental health service is developed collaboratively with the consumer and other persons nominated by the consumer

Standard 16 Quality Care and Treatment (16.26)

Continuity of care is promoted by ensuring that the views of consumers, their family, carers and other relevant service providers are considered and documented prior to administration of new medication and/or other medical interventions (eg involvement of GP, private psychiatrist, case manager advocate in decision making)

1.3 **Strategies for Change**

9. Clinical services have a responsibility to organise regular multi-disciplinary reviews of a consumer's care, involving consumers, support workers. Family, and carers

10. Where significant medication issues have been identified, a case conference should be called.

11. A standard for what constitutes a significant medication issue needs to be clarified

12. Examine current procedures for ensuring hand-over of information and care with staff changes is adequate and assesses level of disruption to care

13. Ensure quality guidelines are established and implemented to guide what information gets shared and how when staff change

14. Audit the quality of information sharing that occurs with staff changes.

15. Undertake annual anti-psychotic medication audits.

16. Key persons involved in the support and care of each consumer need to be identified and involvement negotiated as part of the initial assessment and ongoing management plan with the consumer.

Notes:

Some of these strategies could be supported by implementing a project developed in the day-long workshop held with focus group participants and further developed by Sue Wyeth and Murray Patton where doctors identify five clients with medication issues. The doctors then organises a meeting between all stakeholders involved in supporting the consumer. The meeting would explore the issues and identify strategies for addressing some of these issues. The project will need to include a review of the process to examine how it works.

Issues in relation to continuity of care are linked with broader issues of recruitment, workforce development and strategies for retaining staff. However, at a local level, strategies for ensuring medication treatment documentation is up-to-date and information is shared between all stakeholders involved in any one consumer's care. Strategies need to ensure that staff changes cause the least disruption possible for consumers and families.

2.	**Collaborative relationships between service providers supporting a consumer**

2.1 Issues identified

2.1.1. Issues with building across service collaborative relationships (NGO and SAH staff)

2.1.2. Gaps in continuity of care and sharing of information about medication treatment plans when staff changes and between services

2.2 Relevant National Mental Health Standards

Standard 14 Entry into service

The mental health service establishes clear lines of communication . . . between the community services, and with tertiary services to minimise duplicating collection of consumer data.

2.3 Strategies for Change

6. Audit occurrence of joint planning and sharing of documents between providers involved in a consumers care

7. Audit the quality of information sharing between SAH staff and NGO staff.

8. Continuity of SAH clinical staff associated with supported accommodation.

9. Implement more joint education sessions on medication between SAH staff and NGO staff

10. Clarify expectations and responsibilities for medication in the interface between non-governmental and hospital mental health service providers. Some of these could be addressed at the level of service contracts and the effectiveness of these relationships actively monitored by Counties Manukau DHB.

Notes:

Currently, there are a number of initiatives between SAH and NGO providers involved in mental health service delivery. For example, SAH and Challenge have two joint supported accommodation services. There is a Pathways day programme initiative and the Te Korowai Comprehensive Community Support programme initiative, as well as regular interface meetings between NGOs and SAH team leaders. Despite this significant progress in the last few years, there remain significant issues in the area of building collaborative relationships and confusion around the development of collaborative treatment teams.

A large number of unmet expectations about involvement in the 'treatment team' were identified across the focus groups. Given that the individual consumer's situation and their choices often intimately affect this, who is a part of the treatment team would need to be negotiated on a case by case basis. However some work on formalising this process could ensure this process of negotiation and discussion occurs, and this needs to be evaluated in order to ensure that this occurs in a satisfactory way for all stakeholders.

Dialogue between the NGO sector and the hospital provided services needs to be focussed on clarifying roles and responsibilities between teams in the area of medication, as well as identifying ways to systematically evaluate inter-agency relationships at the level of individual teams. Currently, the emphasis in health systems is on developing seamless service delivery between hospital provided services, NGO provided services and primary care. There is a need to explore the ways in which the above initiatives will further the development of an integrated care model across HHS and NGO providers within Counties Manukau mental health services.

Clarifying the interface between non-governmental and hospital mental health service providers is necessary. It is critical to be clear about what constitutes reasonable expectations in the area of medication of both parties. This may reduce some of the current areas of confusion that service providers experience in this area. At the same time the issues may be reflective of a status difference between clinical hospital staff and non-clinical NGO staff and less experienced staff working in many NGOs.

3.	**Consumer and Family need for Information and Education about Medication**

3.1   Issues identified

    3.1.1 Gaps in the provision of information about medication and illness to consumers, family and carers by service providers.

    3.1.2 Gaps were identified in the following areas:

-    Availability of information
-    Accessibility of information sources
-    Effective delivery of information
-    Appropriate level of information
-    Identification of consumer and family gaps in knowledge
-    Timeliness of information giving

3.2   Relevant National Mental Health Standards

Standard Five: Rights (5.9)

The mental health service provides consumers, their families and their carers with information about available mental health services for mental illness and mental health problems and available treatments and support services relevant to their condition

Standard 15 Consumer assessment (15.9)

Where a diagnosis is made, consumers, their family and carers, with the consumer's consent, are provided with information on the diagnosis, options for treatment and possible prognosis.

Standard 20 Promoting Mental Health and Community Acceptance (20.2)

The mental health service provides information to other services and actively works with consumer groups to provide information about mental illness and mental health problems as well as factors that prevent mental illness and mental health problems

Standard 16 Quality Care and Treatment (16.10)

The consumer is informed by the mental health service of the potential benefits, potential adverse effects, financial costs and any other predictable inconvenience associated with the provision of a particular treatment or therapy.

Standard 16 Quality Care and Treatment (16.19)

The consumer is provided with understandable written and verbal information on the potential benefits, adverse effects, costs or and alternatives to the use of medication and other medical interventions, and, with the consumer's consent, their families and carers may be provided with the same information

3.3 **Strategies for Change**

3.3.1. All clinical services have a responsibility for knowing how to access up-to-date written/audio visual material on mental illness and medication treatments, and ensure that these resources are readily available to staff, families and consumers.

3.3.2. Information availability needs to be audited. Consumers and families need to be a part of the processes of auditing information availability in order to ensure that information meets their needs.

3.3.3. Evidence of information sharing with consumers and family needs to be provided in the case notes.

3.3.4. Some form of auditing and assessing both the occurrence and the quality of information sharing needs to be implemented. Consumers and families must be involved in the evaluation of information sharing.

3.3.5. Collaboration between mental health services and drug companies to develop information packages about medications could be explored.

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4. **Staff need for information about medication**

4.1 **Issues identified**

4.1.1. Gaps in staff knowledge about medication and its effects

4.1.2. Gaps in staff skill in assessing consumer, and/or family information needs about medication and diagnosis.

4.2 **Relevant National Mental Health Standards**

Standard 12 Leadership and Management (12.11)

The mental health service regularly identifies education/training and development needs of its staff and ensures that the necessary skill mix is evident to deliver on the core functions of the service

Standard 12 Leadership and Management (12.12)

The mental health service ensures that staff have access to, and are able to participate in, an education and professional development programme that targets their specific learning needs

Standard 11 Prevention and early intervention (11.6)

The mental health service involves consumer support groups in provision of relevant education where practicable

Standard 16 Quality Care and Treatment (16.14)

The consumer is supported to make an informed choice on the most acceptable form of therapy from the range of available options.

Competencies for Mental Health Workers
In addition, the report '*A Competency Framework for the Mental Health Workforce'* (July 1999) published by the National Mental Health Workforce Development Co-ordinating Committee, identifies the following in its core basic competencies that are relevant to the issues outlined above.

- Demonstrate knowledge and understanding of mental health and illness, and treatments.
- Communicate effectively through 'use of appropriate communication style, level and medium for the consumer, the group and the setting'.
- Promote health and wellness of consumers, families and communities through ensuring that 'consumers and their families/whanau/resource group have access to relevant information, pertinent education, and support in relation to the diagnosis, illness and mental healthcare options available'

4.3 **Strategies for Change**

4.3.1. Identification of staff learning needs in the area of medication and diagnosis, and identification of treatment options

4.3.2. Assess and train staff in assessing consumer and family knowledge about medication, knowledge of treatment options and diagnosis.

4.3.3. Development of staff skills to improve effective delivery of information and support consumers in making informed decisions.

4.3.4. Each team to have identified family and consumer representatives working alongside clinical staff to improve delivery of information.

4.3.5. Develop benchmarks to measure quality of delivery and provision of information about medications

4.3.6. Develop a regional database that identifies available information resources and training courses or materials on medication, treatment options and mental disorders, that identifies how to access them, key audience, key topic, quality and level of complexity of the information.

Notes

Developing a regional database that identifies available information resources and training courses or materials on medication and mental disorders, how to access resources, key audience, key topic, quality and level of complexity of the information could improve use and delivery of information about medication treatments. This would require a commitment to regularly updating information. It may be that this information is already available from such organisations as the Mental Health Foundation. It may be that a project that rather than developing new resources, instead addresses questions of information accessibility, some form of identifying level of complexity of the information, suitability for which audience and key topic areas may need to be developed in dialogue with service providers and users.

Not identified in the focus groups, due to sample bias, were the education and information needs of service users and families with first languages other than English. This is an area that would warrant further exploration and development of resources.

5.	**Resource Issues**

5.1 **Areas of Concern**

5.1.1 Resource limitations were often identified as affecting staff capacity to deliver quality care and at times compromising standards of care. Resource issues that impact on individual consumers and staff were highlighted in the following areas:

- High doctor and key worker caseloads
- Lack of vehicles for community key workers
- Lack of subsidy on some medications
- Perception of prescribing inferior medications due to best medications not being available in New Zealand or subsidised by PHARMAC

5.1.2. Few treatment options offered or given other than pharmacology within HHS mental health services

5.2   **Relevant National Mental Health Standards**

Standard 16 Quality Care and Treatment (16.16)

Medication and other medical interventions used reflect internationally accepted medical standards

Note: What is interesting about this standard is the focus on 'internationally accepted' rather than 'best practices, in light of the focus of treatment and care focused on best practices and the use of evidenced based guidelines. It is an interesting contradiction that clinicians and consumers have to work with.

Standard 16 Quality Care and Treatment (16.13)

The mental health service provides access to a range of therapies based on the needs of the consumer

The resource issue needs to be addressed in relation to:

(a) high levels of deprivation in Counties Manukau and greater resourcing required as a consequence.

(b) equity issues in terms of equitable accessibility of non-subsidised medications in situations of treatment resistance or side effects using subsidised medications and side effects of subsidised medications.

(c) The view that inferior drugs are being prescribed needs to be explored.

5.3   **Strategies for Change**

5.3.1 The impact of resource limitations on quality of care needs to be reviewed. Specific resource issues to be reviewed include:
- Assess need for vehicles
- Assess and audit caseloads using an instrument such as the Denver Acuity Scale

5.3.2 Clinical staff could document situations where inequality occurs in medication options due to lack of subsidy and where the prescribing of inferior medications results in poor treatment outcomes.

5.3.3 Identification of services providing alternative treatment options and assessing the accessibility of these alternatives

Notes:

Work in this area is already taking place at Ministry of Health, Mental Health Commission, the hospital and DHB levels, eg high users research, deprivation and service utilisation studies. . Identifying the ways in which shifts/increases in resources available impact on improvements to the management of medication across the sector will be critical. This involves a combination of identifying where shortage of resources impact negatively on service delivery and exploration of potential improvements in resource distribution. Another major area that appears to warrant consideration is the availability of subsidised medications through PHARMAC. This was a frequent experience of injustice identified by consumers, family and staff.

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6.   **Recovery Oriented Service Delivery**

6.1   **Areas of Concern**

6.1.1. Examination of how staff work with the tensions between use of compulsory treatment orders and utilisation of recovery oriented practices in mental health services

6.2   **Relevant National Mental Health Standards**

Standard 16 Quality Care and Treatment (16.4)

The mental health service provides a range of treatment and support services which are specific to a consumer's stage in the recovery process.

6.3 **Strategies for Change**

6.3.1. Development of a project exploring how staff and consumers work with the tensions between use of compulsory treatment orders and utilisation of recovery oriented approaches in mental health services.

6.3.2. Assessing staff utilisation of a recovery oriented approach in service delivery

Notes:

Currently, there is some discussion about the issue of compulsory treatment orders and consumer rights (eg upcoming workshop in Auckland). This area presents a key tension in the development and implementation of treatment plans within the context of recovery-oriented services. Developing an understanding of how staff, service users and families manage this tension could enhance the development of recovery oriented service delivery across all sectors.

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