



‘They just don’t care’: The experiences of mental health consumers in a Queensland bush community

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Abstract

This paper examines the experiences of mental health consumers in a rural community. It is the result of research undertaken in ‘Ruraltown,’ a Queensland rural community, to determine the influence of bush identity on attitudes to mental health. During the course of this research, the negative plight of mental health consumers in the community became apparent. Through questionnaires and interviews with consumers, it was discovered that they felt discriminated against, alienated, disempowered, unsupported and alone. Although consumer input has been acknowledged as essential to mental health reform in recent years, this paper argues that there is still a long way to go. Issues identified by Ruraltown consumers include the negative perception of mental health issues, barriers that they encounter, stigma, and service provision problems. Lack of understanding and support from the community was also raised by consumers as compounding their isolation. The paper concludes with recommendations to enhance the situation for mental health consumers, not only in Ruraltown but in all rural communities. These include increased consumer involvement in mental health awareness, promotion and educational activities, improved service provision and, most importantly, ways to empower and encourage mental health consumers to become valued community members.

Keywords

rural mental health, mental health consumer, carers, stigma, mental health policy

Introduction

Many mental health consumers have negative experiences resulting from the stigma and misunderstanding surrounding mental health problems. The unique conditions that exist in the bush - such as lack of services, distance and isolation, confidentiality concerns, fear of gossip, and cultural differences - that render conventional service methods inappropriate and problematic, can compound these negative experiences. This paper addresses the experiences and attitudes of mental health consumers in a Queensland bush community and highlights the very real problems they face as a

result of stigma, ignorance and service provision issues. It argues that education and cooperation is needed to dilute the powerful stigma attached to mental health issues. Although there has been acknowledgement of consumer issues in government policy over the last 20 years, it is argued that rural consumers remain a seriously disadvantaged group. The value of consumer consultation and involvement in policy or promotional activities is also considered.

Consumer recognition in mental health policy

In recent years, there has been political acknowledgement of consumer and carer issues. Since the issue of mental health became a

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pressing political concern towards the close of the 20th century, increasing consumer and carer advocacy and involvement has been part of government strategy. National mental health policies and Queensland strategies have focused on rural concerns and consumer issues. The Federal Government recognised the extent of mental health problems in the general community and developed the *National Mental Health Plan* (Australian Health Ministers, 1992) as part of the National Mental Health Strategy. In broad terms, the strategy advocated structural reform of mental health services with an emphasis on community-based care and integration of services.

Community mental health services improved and increased dramatically as a result of this strategy. However, stigma and discrimination surrounding mental illness remained. It was against this backdrop that the *Second National Mental Health Plan* (Australian Health Ministers, 1998) was formulated and endorsed by all Australian Health Ministers, continuing the agenda for mental health policy reform. The plan embraced the objectives of the first and introduced further priority areas for reform: promotion and prevention, development of partnerships in service reform, and quality and effectiveness of service delivery (Australian Health Ministers, 1998, p.6). The importance of fostering partnerships between health and service providers, and carers and consumers in the community was emphasised, and rural and remote communities were identified as a priority target group.

A third *National Mental Health Plan 2003-2008* was released in July 2003. The goals of this plan were to focus on mental health promotion and the prevention of mental health problems. Increasing the responsiveness to consumers and carers across all mental health and related services was also recognised as a priority (Australian Health Ministers, 2003, p.3).

The *Ten Year Mental Health Strategy for Queensland* (Queensland Health, 1996), incorporated elements of the Australian National Mental Health Strategy. The Queensland strategy (Queensland Health, 1996, p.4) states that 'the central principle for planning and delivering mental health services is that they must target the needs of consumers and

demonstrate the effective use of resources in meeting these needs.' People from rural and remote communities of Queensland were identified as having special mental health requirements. Once again, the needs of consumers and carers were highlighted.

Due to the emphasis on consumer and carer participation, the Queensland Mental Health Consumer Advisory Group (QCAG) was established in 1993. This was a Ministerial Advisory Group whose aim was to provide strategic advice to the Queensland Minister for Health about mental health consumer and carer views on the provision of mental health services in the state. The Group also sought to promote the meaningful involvement of consumers, carers and families in the planning, delivery and evaluation of mental health services. The aim was to support and encourage the establishment and development of consumer and carer advisory groups (CAGs) at local levels for all mental health services in Queensland. CAGs were also encouraged to advise mental health services at the local level. There were over 30 local CAGs in Queensland in 2001. However, since then, there have been reports of significant problems with funding and support for the CAGs. These groups are no longer funded or operating in Queensland.

The purpose of this summary of recent government policies and strategies is to highlight government rhetoric about targeting consumer and carer needs, and to enhance their involvement in the delivery, management and promotion of mental health. However, it can be argued that this rhetoric does not translate into reality (see Hickie, Groom, McGorry et al., 2005). The Ruraltown study highlights some of the real problems consumers still face, especially in rural communities.

The Ruraltown study

This paper resulted from research conducted in a Queensland bush community from 2002 to 2004, as part of a doctoral dissertation entitled 'The influence of bush identity on attitudes to mental health in a Queensland community' (McCull, 2005). To protect the identity of people involved in the study, the community was called 'Ruraltown.' Community members, mental health consumers and service providers were canvassed by questionnaires and interviews to

ascertain views about attitudes to mental health, services and other factors affecting mental health in the community. However, in the process of this research, it became apparent that the experiences of mental health consumers in Ruraltown were very negative. They had the unique perspective of a marginalised group, feeling abandoned, alone and rejected, and receiving little support or involvement in service provision or promotion activities.

Although this research focused on only one bush community, many other studies (Alston & Kent, 2004; Botterill & Fisher, 2003; Bourke, 2001; Cheers, 1998; Dunn, 1996; Fuller, Edwards, Proctor & Moss, 2000; Gray, Lawrence & Dunn, 1993; Hickie, et al., 2005; Humphreys, 1999; Rajkumar & Hoolahan, 2004; Stehlik, Gray & Lawrence, 1999) have also revealed that, due to conditions such as isolation and lack of services and support, mental health consumers in the bush may experience this discrimination more acutely. As Fuller et al. (2000, p.152) argue, 'the circumstances of rural and remote communities do have an effect on the manifestation of, and response to, mental health distress. These circumstances are the culture of self-reliance and the economic hardship, trauma and isolation that these communities endure.' By acknowledging the experiences of rural consumers, much can be done at a grass-roots level to help alleviate these problems. Stacey and Herron (2002, p.12) maintain that 'consumer perspectives are critical to evaluation and research efforts, despite the fact that such involvement is a rare phenomenon.' The aim of this paper was to give Ruraltown consumers a voice, to highlight the problems they experience, and to determine what can be done to improve the plight of mental health consumers in rural communities.

Mental health services in Ruraltown

There were three major mental health services consulted in the Ruraltown study: the Mental Health Service (MHS) operating within the Primary Health Care Unit (PHCU) under the auspices of Queensland Health, and two non-government organisations - the Neighbourhood Centre and Anglicare. The primary health care role of the MHS was to educate the community about mental health, provide crisis intervention where possible, and to facilitate and support the CAG. The Neighbourhood Centre, a

philanthropic organisation that was established in 1980, provides the community with services such as family support, emergency relief, and home and community care. A Family Worker also counsels families in need. The Ruraltown Anglicare Centre's main focus was mental health support for the community. A Mental Health Family Support Service assisted and resourced families affected by mental illness. Mental health support workers were also available to provide non-clinical counselling and guidance.

Of particular relevance to this research was a Community Participation Project that commenced in Ruraltown in 1999, under the auspices of Anglicare Western Region. It was an initiative of Queensland Health, in response to the national strategy for mental health services reform. The position of Mental Health Community Development Officer (MHCDO) at Anglicare was funded by this project for a period of three years. The main focus of the project was to promote and improve consumer and carer participation. It was very much a consumer-focussed project, advocating participation and partnerships in service planning, delivery and evaluation, to develop strategies to facilitate mental health promotion, prevention and early intervention.

As part of this broader project, a Mental Health Promotions Project commenced in Ruraltown in September 2001, under the supervision of the MHCDO at Anglicare. This project was based on community development principles and emphasised consumer participation that aimed to give consumers a voice in their treatment, rather than adopting a provider-centred approach. Promotion of mental health was effected through radio segments, information brochures, and a mental health awareness forum in April 2002. The MHCDO also formed a Mental Health Interest Group (MHIG) for consumers, carers and other interested people. The Group met regularly for support and to address members' concerns. Membership rose to approximately eighteen by April 2002.

The MHCDO encouraged and supported this Group through the transition of formalising into a CAG. However, this process lapsed when funding for the position was terminated in June 2002. Despite the considerable progress that had been made in spreading the mental 'health'

message and supporting mental health consumers and carers, the loss of funding meant that there was no longer a worker whose role was to promote mental health and consumer involvement in Ruraltown. The responsibility of assisting with the transition of the MHIG to a CAG was then transferred to the PHCU in June 2002. A CAG was finally established in Ruraltown in December 2002.

Method

Participants

Consumer perspectives about attitudes to mental health in Ruraltown were obtained by contacting the (former) President of the CAG, to ask if members would consider being involved in the study. At that time (i.e., 2002), there were only eight CAG members but the President was confident that all would be willing to participate in any study aimed at improving attitudes to mental health in the community. The CAG consisted of some of the mental health consumers that utilise services available through the Mental Health Unit (MHU) in Ruraltown. Due to the sensitive nature of the study and issues of confidentiality, the CAG respondents were the only consumers who could be identified and invited to participate in the study.

Procedure

Questionnaires were given to the eight CAG members in October 2003 and all were returned over the following month. Questions that were asked in the interviews and questionnaires revolved around attitudes to mental health in the community, and included:

- Do you think the term ‘mental health’ is a positive or negative concept, and why?
- Are bush people inclined to seek help for mental health problems, and what are the major barriers to help-seeking?
- Is there a stigma attached to the concept of ‘mental health’ and, if so, why?
- Are there unique conditions in the bush that affect people's mental health and what do you believe these are?
- Are you aware of the mental health services available and do you believe these are adequate?
- Can you make any suggestions to improve attitudes to mental health in the community?

Findings

Questionnaire responses

Although the number of consumers involved in this study was small, and the questionnaires were answered briefly, the responses were enlightening and informative. When combined with other Ruraltown interview and questionnaire results, anecdotal evidence and the findings from other studies, they paint a bleak picture of the consumer experience.

All eight CAG respondents believed the term ‘mental health’ to be a negative one and four gave a reason for this. These reasons were to the point:

‘Because people don’t want to know about it.’

‘It doesn’t sound nice.’

‘No one cares.’

‘When people hear ‘mental’ they shut you out, it is their fear and they think we should be locked up. This is a great tragedy and why there are so many suicides. No one wants to listen.’

All respondents believed that bush people were not inclined to seek help for mental health problems, with shame and embarrassment being the predominant reasons, followed by fears about confidentiality and gossip, lack of knowledge about mental health issues, and a shortage of services and providers. Once again, all CAG members believed there was a stigma attached to mental health in the bush. Responses included:

‘People don’t care.’

‘Mental’ is a dirty word.’

‘Doctors, nurses and general people don’t give a damn.’

‘Because people in the bush need to think they have to keep a stiff upper lip. They are worse at admitting there is a crisis level problem than city people.’

Unique conditions in bush life that affect people’s mental health were also identified. These conditions again revolved around the stigma attached to mental health problems and the limited treatment options.

‘No one wants to know you, they treat us as if we have a death illness, we lose our friends, no one cares, the hospital is the worst. They just do not want us there.’

‘Just the way people are.’

‘Financial, distance, no real help.’

‘There [are] not enough [services].’

'We live too far from the help we need. Phone calls never get returned, appointments are not kept - this makes us feel more unwell.'

It was unanimously agreed that mental health services in Ruraltown were inadequate. The reasons given resonate with personal despair and feelings of neglect:

'They just don't care.'

'No one wants to know you.'

'Because no one wants to take the time to care. Phone calls are not returned. We sit by the phone waiting for mental health to call back all day and you are let down. It is very difficult when you live on your own on a property one hour and 20 minutes away.'

'Because people don't tend to talk about their problems in public, therefore less people talk about where to go for help.'

'Lack of money for people to get help. Anyone with depression does not read the papers or watch TV, they are on their own.'

Five respondents made suggestions to encourage awareness and promote mental health in rural areas. These included:

'Get people to come and talk to us and get our stories to the top health officials.'

'Get more services, remove the stigma, have more psychiatrists and psychologists in the bush.'

'The people with all sorts of mental illnesses should come together and talk to the people that make the decisions for us. It is only us that go through it who can tell people what it is like, and then they might change the way they treat us.'

'Change the name from 'mental'. People think you will give them a disease. More education has to be done for us, more money spent to help us in the bush, more support given as we feel we are on our own. Christmas is the worst time for us and everything is closed down.'

'HELP HELP HELP HELP!'

These responses, particularly the last one, suggest that, for those who suffer from mental health problems in Ruraltown and who are most affected by negative attitudes to mental health, the situation is desperate. The feeling of abandonment and isolation is palpable. It could be argued that, due to their negative experiences of mental health issues, their feelings of frustration and desperation might have been intensified. However, the lack of empathy and understanding that these people feel signifies that there are very real problems in the way

mental health issues are dealt with in the bush. Characteristics of bush culture such as self-reliance, stoicism, impassivity, and toughness, combined with isolation from mainstream mental health services, compounds their alienation and isolation even further.

Other problems facing Ruraltown consumers

In addition to isolation, stigma, service provision problems and community estrangement, Ruraltown consumers must contend with other difficulties. The CAG was to be the consumer's voice in the community: to assist in empowering consumers and carers to contribute and respond to the National Mental Health Plan in the Ruraltown area. In addition, the CAG was to be an avenue for input and involvement in decisions made on policy, plans and services affecting Ruraltown. However, progress towards these goals has been considerably thwarted for Ruraltown consumers.

All members were keen to keep the CAG going but were disappointed by the lack of support or encouragement they received. One member stated that:

'No one really wants to know what we've got to say. No one wants to talk about the CAG but we don't know what we're doing.'

Another member raised a concern about funding for the CAG, arguing that:

'We're not asking for mountains of money, but just some guidance would be good. After all, the Group is for consumers, not providers.'

The issue of funding was also raised at the CAG Conference in Brisbane in 2003 and was expressed as a challenge facing many CAGs in Queensland. Problems such as lack of funding from local mental health services, lack of clarity about how the funding can/should be used, and limited control over the use of the funding, were recognised. It appears to have been a bureaucratic financial dispute that needed clarification.

Other problems identified at the CAG Conference echoed the Ruraltown CAG concerns: how to get a CAG started, how to keep a CAG running, particularly when most of its members have periods of unwellness, how to attract members, how to foster genuine partnerships, how to get a CAG listened to and taken seriously, and challenges around the

interpretation of consumer participation. These are significant problems for consumers who are aiming for empowerment and some control over their lives. A Ruraltown informant stated that:

'the biggest problem for the CAG is that you are dealing with people who have their highs and lows of depression. You can't expect them to be functioning without support to administer the group... They are not listening to the consumers' needs.'

One consumer summed up his feelings about mental health services in Ruraltown:

'Mental health care in Ruraltown stinks. They think we're a waste of time.'

At Ruraltown Base hospital, there was no provision for an inpatient mental health bed. However, if there was a mental health emergency, there was no other after-hours facility; the only option was to attend the hospital. As qualified staff may not have been on duty to attend to a mental health crisis, police were often called in, potentially aggravating matters even further. One consumer relayed the story of how she was taken by police car, against her wishes, to the psychiatric hospital in a larger regional centre. She stated that, *'I felt like a criminal.'* A similar incident was reported by a rural consumer in a study by Hickie et al. (2005, p.403): *'if consumers need acute care (in a country centre), they have to be taken to a GP, and then tranquilised and strapped to a stretcher to be transported to Perth. I was told, when I was suicidal, to drive myself to the city.'*

The same Ruraltown informant had also been a patient in the Ruraltown hospital for depression and anxiety. She maintains that,

'There are huge problems with the hospital. They don't want any mental health patients there. They think you are wasting their time. They don't care and they don't understand.'

On a later occasion, she was admitted to hospital for a 'physical health' reason. She described that, *'The same nurse who was there when I was in for depression stated: Oh, are you back in for another holiday luv.'*

Needless to say, this attitude is unfortunate when treating any patient, not less a mental health patient.

All members of the Ruraltown CAG were long-standing community members and commented that they want to belong and be accepted as 'normal residents.' However, the discrimination

and rejection they felt from the community through their 'assignment' as mental health consumers precluded this. When asked what can be done to help mental health consumers in Ruraltown, one consumer stated:

'We need to break down the barriers. We need people to understand that it is a day to day battle. If this is happening to me, how many others are affected? We need help to progress through our mental illness and we need constant support, not just 'bandaid' treatment. They need to listen to us.'

As Alliston (2002, p.7) argues, 'too often the focus is on treatment, prognoses and the next medical appointment. It must be remembered that people with a mental illness are people first.'

Discussion

One of the most important findings of the Ruraltown study was that the mechanisms in place to support mental health consumers were not working as effectively as they might. The Ruraltown CAG was formed to provide empowerment and encouragement for consumers. Despite some initial progress, the Group no longer remained viable, and this was perceived to be due to a lack of support, interest or guidance. At the time of writing, it was discovered that CAGs were no longer supported through Queensland Health, and that the Ruraltown CAG had dissolved. In a telephone interview in early 2006, the former President of the CAG stated that,

'Nothing has changed. We get no support. Nothing was organised by the MHS for Mental Health Week in October 2005. The MHS in Ruraltown may as well not even exist.'

For mental health consumers to feel truly empowered, the above concerns need serious consideration. Although these problems are not unique to Ruraltown, they need to be addressed before consumers in this community feel they have some control over the management of their lives and mental health. If financial and administrative assistance is not delivered, if the encouragement needed remains in short supply, and unreasonable restrictions are in place, the alienation and 'otherness' that these consumers experience will be compounded. Judd, Murray, Fraser et al. (2002, p.297) argue that 'consumers and staff of mental health services are well placed to identify patterns and develop hypotheses about barriers to help-seeking in a

particular community.’ It is essential that mental health consumers in Ruraltown be given a voice, to express their concerns, experiences and grievances - and be empowered in the process.

It was recommended by Betts and Thornicroft (2001, p.19) in the *International Mid-Term Review of the Second National Health Plan* to ‘expand and enhance the consumer and carer network ensuring their ongoing involvement in policy and program planning, and fund the necessary administrative capacity.’ This was especially true for rural communities, where smaller populations, isolation, and a lack of services and support further segregated consumers. As a result, in *National Mental Health Plan 2003-2008*, increased consumer and carer consultation is recognised as vital for the promotion of mental health and the prevention of mental health problems, and is to be afforded ‘high priority’ (Australian Health Ministers, 2003). However, as is evident in this study, policy does not yet seem to be translating into reality.

Several recommendations are listed below to improve the experience of mental health consumers in rural areas. Although they are based on the findings from the Ruraltown study, it is possible that they can be extended to other Australian regional and rural communities. This assumption is supported by findings from other rural studies and extensive anecdotal evidence.

An alternative term to ‘mental’ should be used for referring to mental health services, programs or consumers. It seems to create real fear in people who are not familiar with the intended positive meaning of ‘mental health.’ Changing the term may make help-seeking more acceptable and dilute the stigma that is attached to being a ‘mental health consumer.’ Furthermore, ‘health’ needs to be viewed holistically as the division between physical and mental health has proven to be counter-productive in perception and practice in rural areas.

Community education about mental health should become a priority, to reduce discrimination and alienation for consumers. Education needs to be accessible and sensitive to the mores and traditions of rural areas. To enhance attendance at public meetings, seminars or workshops, it is also recommended that terms

such as ‘positive living’ or ‘holistic health’ could be considered. If providers are truly committed to ensuring consumer empowerment and understanding, surely some progress can be made here. As Herrman (2001, p.716) concludes, ‘promoting community understanding about the nature of mental health and mental illness is the key to changing the policies and practices in education, employment, law and health which are critical to mental health. Respect for the human rights of those with mental illness is the first step to improving treatment and care services.’ Alliston (2002, p.7) takes this one step further and suggests that ‘if we can encourage the community to understand that all people are potential consumers and carers and that any one of us may at some time be dealing with an unexpected struggle with mental illness, we could go a long way to reducing stigma and promoting social inclusion’ (see also Wainer & Chesters, 2000).

Consumer participation is crucial to this process. Stacey and Herron (2002, p.13) conclude that ‘if we are committed to promoting mental health, then consumers are non-negotiable, vital partners in evaluation processes.’ This was one of the aims of forming CAGs in Queensland; however, as demonstrated in this study, the task has been problematic. Humphreys et al. (2002, p.10) argue that ‘it is very easy to talk about ‘real consumer involvement at all levels’; it is quite another matter altogether to put it into operation effectively.’ It is evident from this study that this is what is urgently needed for consumer empowerment in Ruraltown.

As suggested by Clark (2003), adequate mental health training and education needs to be provided to hospital staff and at least one permanent bed should be allocated for mental health patients. The police also need adequate training in how to recognise mental health problems and appropriately respond to a crisis involving a mental health consumer.

Funding should be sought for a health promotion officer who is responsible for mental health promotion and improving attitudes to mental health in Ruraltown. The primary responsibilities of this worker would be to the consumer: to provide guidance and encouragement and to ensure that consumers have input into the planning and delivery of mental health services

and educational activities. The health promotion officer could also act as a first point of contact for potential clients or referees, provide information on request, organise promotional activities, and be available for mediation between services and consumers, if required.

It is recommended that mental health positions or programs run for a minimum of five years to allow adequate time for progress to be made. It has been found in this study that positions or programs that have been funded for only three years or less have been ineffective due to lack of time for education about services, community acceptance or gaining the trust of clients. It has also been shown that consumers do not receive on-going support and can experience distress, frustration and relapses in their conditions due to constant staff changes or the early cessation of mental health programs.

A support group should be formed, with the assistance of the health promotion officer, for all consumers and carers in Ruraltown, and not only those who are treated by the MHU. This would provide support and encouragement to all those affected by mental health problems, enabling them to be empowered and gain mutual benefit through shared experiences, and perhaps to feel more accepted by the community.

Government and community agencies in Ruraltown should work together to improve the situation for mental health consumers. This can be achieved by holding inter-agency meetings to improve knowledge, communication and referral between the services, enhance collaboration and cooperation, and reduce the duplication of services. It is clear from this research that services in Ruraltown are not collaborating as effectively as they might in supporting the consumer.

Conclusion

This article has addressed the experiences of mental health consumers in a rural community in Queensland. Despite recent government recognition of the needs of consumers and carers, there still appears to be a dearth of support and acknowledgement of the problems faced in rural communities. The Ruraltown study highlights the very real issues that affect consumers in the community. The negative reports from Ruraltown consumers, and the

alienation they feel, abundantly illustrate that more needs to be done to support mental health consumers, especially in rural communities. Consumer consultation and involvement across the whole mental health spectrum is vital to achieving consumer empowerment and improving the quality of consumers' lives.

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