

National Study of Psychotic Disorders in Australia: Feedback from Individuals with Psychosis

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Abstract

Objective: Key findings of the Australian Study of Low Prevalence (Psychotic) Disorders were reported back to a group of individuals with psychosis from 1 catchment area included in the survey with the aim of obtaining their comments and responses.

Methods: The presentation was a dynamic, interactive encounter between people with psychotic illness, researchers, and mental health professionals. In addition to the presenter, session moderator, and 4 other mental health workers, 13 residents of an inner city hostel in Perth, all of whom had a diagnosis of schizophrenia were included. A set of illustrative and simplified overheads was used to present the study findings to the hostel residents, who were encouraged to ask questions and provide comments during and after the presentation.

Results: Hostel residents with psychosis demonstrated a complex, multi-faceted awareness of their disorder and its impact on their lives, and their responses shed light on some of the challenging findings of the study. The comments, questions, and issues raised by the residents were related to the study results that evoked their experiences of having a mental illness, being socially isolated, and living in the community with limited support.

Conclusion: The presentation was a unique example of participatory action research in that it completed the feedback loop from survey population to researcher and back to survey population.

Key words: Participatory action research, Rehabilitation, Psychosis, Social isolation

Acknowledgement

The data presented in this paper were collected in the framework of the Collaborative Study on Low Prevalence (Psychotic) Disorders, an epidemiological and clinical investigation which was part of the National Survey of Mental Health and Wellbeing, Australia, 1997 to 1998. The members of the Low Prevalence (Psychotic) Disorders Study Group are: Professor Assen Jablensky (Project Director and Team Leader, Western Australia); Professor Vaughan Carr (Adviser); Dr David Castle (Deputy Team Leader, Western Australia); Dr Mandy Evans (Team Leader, Australian Capital Territory); Professor Oye Gureje (Deputy Team Leader, Victoria); Dr Carol Harvey (Deputy Team Leader, Victoria); Professor Helen Herrman (Team Leader, Victoria); Mrs Ailsa Korten (Statistician); Associate Professor John McGrath (Team Leader, Queensland); Ms Vera Morgan (Project Database Manager). Other investigators at the four sites included: Scott Henderson, Stephen Rosenman, Jo Medway (Australian Capital Territory); David Chant, Susette Cardy, Chris Young, Ben Chapple (Queensland); Ian Gordon, Tom Trauer, Helen Evert, Tony Pinzone (Victoria); Anna Waterreus (Western Australia). A complete list of the investigators is available in: Jablensky A, McGrath J, Herrman H, Castle C, Gureje O, Morgan V, Korten A, on behalf of the study group (1999). *People Living with Psychotic Illness: An Australian Study 1997-98. National Survey of Mental Health and Wellbeing: Report 4.* Canberra: Australian Mental Health Branch, Commonwealth Department of Health and Aged Care; 1999.

Ethics approvals for the study were obtained from relevant institutional ethics committees. Full details are available on request. The study was funded by the Commonwealth Department of Health and Aged Care for those components carried out in Brisbane, Melbourne, and Perth. The component carried out in Canberra was funded separately by the Australian Capital Territory Department of Health and Community Care, and The Psychiatric Epidemiology Research Centre, Australian National University. This paper also acknowledges, with thanks, the hundreds of mental health professionals who assisted in the preparation and conduct of the survey and the many Australians with psychotic disorders who agreed to participate. Without them, this study would not have seen the light of the day.

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Submitted: 13 September 2001; **Accepted:** 15 November 2001

Introduction

The Study of Low Prevalence (Psychotic) Disorders was conducted in catchment areas across 4 Australian states. A 2-phase strategy was used. First, persons living in the catchment areas were screened for psychosis during a

Table 1. Summary of findings from the Australian Study of Low Prevalence (Psychotic) Disorders 1997-1999 (based on 980 respondents).

	Number (%)
Course of psychotic disorder	
Single episode, good recovery	83 (8.5)
Multiple episodes, good recovery between episodes	203 (20.7)
Multiple episodes, partial recovery between episodes	270 (27.6)
Chronic, with little deterioration	197 (20.1)
Chronic, with clear deterioration	227 (23.2)
Impairments, disabilities and lifestyle variables	
Impairment and disability	
Experiencing treatment side effects (if currently using medication)	711 (84.1)
Impairment in daily life due to side effects of medication	619 (63.2)
Dysfunction in work performance in past year (including work, home duties, study)	173 (46.3)
Dysfunction in socialising in past year	579 (59.1)
Dysfunction in maintaining intimate relationships in past year	383 (39.1)
Dysfunction in participation in household activities in past month (if living in household)	253 (49.1)
Dysfunction in caring for self in past month	292 (29.8)
Dysfunction in maintaining interests in past month	388 (39.6)
Satisfaction	
Mostly satisfied with current level of independence	583 (59.5)
Mostly satisfied with life as a whole in past year	429 (43.8)
Other ('lifestyle')	
No regular occupation (including work, home duties, study) at time of interview	706 (72.0)
History of alcohol abuse/dependence	294 (30.0)
History of cannabis abuse/dependence	246 (25.1)
History of other substance abuse/dependence	129 (13.2)
Attempted suicide, self-harm in past year	162 (16.5)
Arrested in past year	100 (10.2)
Victim of violence in past year	172 (17.6)
Felt unsafe in current locality in past month	150 (15.3)
Use of treatment services in past year	
Inpatient services	506 (51.6)
Outpatient services	589 (60.1)
Emergency services	430 (43.9)
Participated in a rehabilitation program	187 (19.1)
Received drug/alcohol counselling	22 (2.2)
Visited general practitioner	797 (81.3)
Visited private psychiatrist	239 (24.4)
Visited private psychologist	65 (6.6)

census month in 1997 at designated recruitment sources, including inpatient and outpatient services, general medical and private psychiatric practices, and points of contact for those with psychoses who were living in marginalised settings and were out of contact with mainstream services, for example, refuges, shelters, and soup kitchens. 5710 people were screened, 3800 of whom were positive for psychosis. 980 of the individuals who were screened were randomly selected for interview.

The survey established prevalence estimates for psychotic disorders in predominantly urban Australia. It found that 4 to 7 persons per 1000 adults resident in urban areas (weighted mean, 4.7 per 1000) were in contact with mental health services during any given month because of symptoms of a psychotic disorder. Schizophrenia and schizoaffective disorder accounted for more than 60% of the prevalence of psychotic disorders. At the same time, the survey collected invaluable data on the characteristics of persons with psychosis. A brief summary of the survey

findings is given in Table 1. More detailed information about the survey can be found elsewhere.¹⁻³

A unique opportunity arose in 2000, some months after publication of the first study report,¹ to present the study findings to a group of men with psychosis living at an inner city hostel in Perth that was within the study's catchment area. The experience of reporting the study results back to this group of individuals is described in this paper. This exploration of participatory methods suggests that actively involving those with psychotic illness in the research process through a fully implemented participatory action research model is a feasible and effective means of generating valuable insights into the contextual and other public aspects of psychotic disorders that should be of interest to clinicians, researchers, and policy makers.

Methods

The presentation of the results of the Study of Low Prevalence (Psychotic) Disorders took place at a hostel located

in the inner city area of Perth. The meeting was arranged by the Living Skills Program of the Royal Perth Hospital in Western Australia as one of its community psychiatry outreach activities aimed at long term rehabilitation of individuals suffering from chronic and severe mental disorders.

The key findings of the study were presented in a series of overheads containing simplified and illustrative tables and graphs. The presentation was organised using the following headings:

- what did the study set out to do
- who was interviewed for the study
- what understanding of psychotic illness was gained through the study.

In addition to the presenter, discussion moderator, and 4 other mental health professionals (as observers), there were 13 male residents in the audience. The diagnostic profile and current psychopathology of the participants had a limiting effect on the size of the audience — all residents had been diagnosed with schizophrenia, which was specified as paranoid for 5 patients and 1 was identified as dangerous. The average duration of their mental illness was approximately 20 years. Their ages ranged from 23 to 51 years and the average length of their stay at this particular hostel was 4 years (range, less than a year to 24 years). Most residents had had only 9 to 10 years of schooling, apart from 1 resident who had undertaken tertiary studies. All hostel residents received disability pensions.

The presentation lasted for more than 1 hour. It was a dynamic, interactive session in which the sequencing of the contents and the emphasis given to issues were cued by the themes raised and discussed by the audience as the presentation of results proceeded. The audience was alert, engaged in the presentation and ongoing discussions, thoughtful in their questions and responses, polite in their interactions with the presenter, moderator, and one another. The observing mental health professionals (who were staff of the Royal Perth Hospital and of the hostel) kept their comments to a minimum, on the whole responding to direct questions only.

The material presented in this paper is based on a qualitative analysis of comments made by the hostel residents. During the presentation, notes were taken by the authors who alternated the role of note-taker. After the session, the authors compiled a more complete record of what had been said and classified the content.

Results

Participants made comments and asked questions about fundamental issues related to the concept of psychosis including definitions and descriptions of psychotic symptoms and experiences. They responded particularly strongly to survey findings on the degree of social isolation experienced by persons with psychosis and with regard to their poor use of rehabilitation services, and their comments on these findings were insightful and illuminating. Their responses, as illustrated below, underlined a willingness to contribute

to and be informed by research in the area of psychotic illness.

The Experience of Psychotic Illness and Social Isolation

Residents quizzed one another on their different experiences of psychosis, on what it felt like to hear voices, what the voices said, and what to do about the voices. Their personal vignettes gave a vivid insight into the experience of psychotic symptoms. When one resident recalled how he had starting hearing voices while still at school and how he had realised only much later that others did not hear voices too, his words struck at the problematic nature of the experience of consciousness. Another resident lucidly articulated the discrepancy he experienced at times, even as he was speaking, between the words in his head and the words he spoke, carefully differentiating between the mere inability to express oneself adequately from a more fundamental breakdown of the linguistic pathway between thoughts and words.

Within the same discussion, a couple of residents quoted the '1 in 5' figure for Australians with a mental disorder at any point in time, a figure which has become very familiar to those working in the area of mental health following the publication of the results of the population survey of mental health and wellbeing among Australian adults.⁴ Several other residents were aware of research into illicit drug use as a precipitating factor in the onset of psychosis, and discussed the potential for marijuana use to cause schizophrenia or exacerbate its symptoms, especially in risk populations.

An enthusiasm for current and comprehensive information on psychosis was well illustrated in the discussion on medication use that followed the reporting of the survey findings in this area. The survey reported that 86% of the study population were receiving medication for mental health-related problems and, although nearly all found that the medication was helpful, a large majority (84%) suffered from treatment side effects and many experienced more than 1, and sometimes several, side effects.² The residents attested to these findings. They also wanted to know more about the consequences of psychiatric medication side effects and the reasons for changing medication, and they proposed inviting a pharmacist with good knowledge of the drugs used for treatment of psychotic disorders to follow up this discussion at a future presentation.

Hostel residents were presented with data on the large number of individuals with psychosis who were socially isolated. These findings resonated strongly with the participants. They responded with both a keen awareness of the burden they created for carers — “There are few carers because it's too hard for them to be with someone with a mental illness” — and an intense sense of the isolation attendant upon having a psychotic illness — “I feel alone and abandoned by my family”. For many, however, the need to be self-reliant was closely connected to their perception of the problems their illness generated for other people.

Impediments to Rehabilitation

Study findings on the rehabilitation of people with psychotic illness were presented in some detail. One of the prime objectives of mental health rehabilitation programmes is to help participants achieve an adequate level of independence, including workforce participation. However, it was noted that participation in the workforce, one indicator of rehabilitation, was low among survey participants and only 1 in 5 of the study participants had taken part in any rehabilitation programme during the 12 months prior to interview.

The discussion on rehabilitation was animated and the residents focused mainly on employment issues. Many spoke of wanting some kind of meaningful work. However, work created a dilemma for them. While one resident believed that receiving a pension made them idle and lazy, another noted that they were liable to lose their pension if they accepted work. Furthermore, there was a fear of being taken advantage of by an employer due to their illness, with one person giving an account of a couple with a disability who had been exploited by working long hours for minimal wages.

A number of residents were loath to seek employment through rehabilitation programmes because of the stigma attached to mental illness — “I want to appear normal, not look abnormal by going through abnormal channels”. Later in the presentation, several residents raised the possibility of an advertising campaign to help reduce stigma. While some participants expressed the humiliation they felt when entering programmes at a level below their perceived capabilities, others were anxious that the psychosis would interfere with their performance if working at a more advanced skill level — “The level of the programs they put you on is often below the level where you think you belong. You feel as though you have regressed”.

At the same time, the organisation and administration of employment services were also given as reasons for not using these services. This supported the survey data which found satisfaction with employment services was relatively low among those using the service.² One resident said that more active assistance was needed from employment staff. He described how hard it was for individuals in his position to approach employers themselves — “Now they just give you the name of a contact to follow up yourself.” Another described a series of unsuccessful attempts to return to the work force — “I wanted to retrain but they just kept giving me benefit forms to fill in. After the third attempt, I gave up trying.” A third resident described the frustration of having work but losing it because he failed to meet the performance level set by his employer — “I had a job but I lost it because I didn’t meet their standard. I could push 8 trolleys at a time, but they said I had to push 12”.

Bleak employment prospects went hand in hand with poor utilisation of drug and alcohol rehabilitation services, despite rates of smoking, alcohol abuse/dependence, and other substance abuse/dependence that were well above rates in the general population. Many used these substances as a form of “self-medication/self-treatment”, especially in the absence of meaningful daily activity. When one resident

responded “What is there to stop for? When you wake up in the morning, what else is there?”, others agreed — “We smoke marijuana because there is nothing else to do”.

The above comments do not sit easily with the finding that 44% of the survey population were mostly satisfied with life as a whole in the past year. Commenting on this statistic, one resident said — “I’m not surprised at that We are satisfied very easily. Just an offer of a packet of cigarettes would make us feel it has been a good day. Or a word, a smile, a place to go.”

Discussion

The presentation of the survey data to this group of individuals completed the feedback loop from survey population to researcher and back to survey population. From a public health point of view, it was an important step towards a model of participatory action research in which the researcher collaborates with those with the problem to help to define and research it, with the fundamental aim of transforming social structures in order to improve the daily lives of the group in question.⁵ The emphasis on change for equity is an integral component of the participatory action research model, something one resident drew attention to unwittingly as he asked — “What will be the real consequences of the survey?”.

Hostel residents with psychosis demonstrated a complex, multi-faceted awareness of their disorder when discussing selected and illustratively presented findings of the Study of Low Prevalence (Psychotic) Disorders. A number of participants had a good grasp of the recent mental health literature in the area of psychotic illness. Most showed a keen interest to learn more about scientific perspectives on psychotic illness and its treatment, and many demonstrated a good capacity for understanding and reflecting critically on the arguments presented to them. All were willing to share their experience of having a psychotic disorder with the researchers present.

The hostel residents identified with 2 survey findings in particular. The first was the degree of isolation experienced by persons with psychosis. These men with psychosis were able to verbalise how their illness behaviour made them too hard to be with and care for, which, in turn, left them alone and isolated. Their expression of the importance of gaining independence was as much about self-preservation in the event of losing, one way or another, those they had come to rely on, as it was about reducing levels of disablement.

The second finding that drew a strong reaction was the poor use made of psychiatric rehabilitation services. The dilemma faced by this group of people with psychosis was the question of the purpose of rehabilitation. The need for meaningful activity arising out of valuable social roles was pervasive; participation in the community through the work role was seen as a primary means of role identification. However, the residents brought up many impediments to achieving this. Their comments highlight the importance of ensuring that any work programme designed for this group

takes into account the seriousness of psychotic illness and its potential impact on participation.

The use of participatory action research models with individuals with psychoses has received little attention in the literature and much of what has been published in this area has had a pragmatic treatment/management focus. Our experience indicates that the participatory action research model is also useful for informing policy makers. In the current study, feeding back research findings to the group under investigation demonstrated the capacity for participatory processes to increase clinicians' and researchers' awareness of how those who suffer from psychotic illness experience their illness and to explore, in depth, barriers to good outcome. The dialogue with residents with psychotic disorders at this inner city hostel indicated that long-term structural changes were required to remove these impediments. In particular, there was a need for an integrated service provision committed to the creation of constructive roles for individuals with psychosis while, at the same time, remaining mindful of the burden of illness that they carry.

For the future, applying the model from a project's inception by involving persons with psychosis as active partners in the design of the research and the formulation of policy is likely to further increase the benefits of the model in terms of the sense of value and dignity it affords

to participants and the insights it generates for clinicians, researchers, policy makers, and the general public.

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* These reports may be downloaded electronically at the following web site: <http://www.health.gov.au/hsdd/mentalhe/resources/index.htm>