

HealthReport

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Welcome to the Pfizer Health Report

Welcome to the Pfizer Health Report. In this issue we focus on the mental health of Australians, looking in particular at schizophrenia and bipolar disorder.

We examine community perceptions surrounding schizophrenia and bipolar disorder, and compare these with the experience of consumers and their carers. Our research findings are supplemented with the views of experts in the field of mental health.

The results of Pfizer's survey indicate that Australians have some knowledge about schizophrenia and bipolar disorder however there are significant differences between community perceptions and the first hand experience of carers and consumers.

This report highlights these disparate perceptions and looks at what has been done, and is being done, to treat, support and build community

awareness for people affected by schizophrenia and bipolar disorder.

Pfizer's survey was undertaken in October 2010 by StollzNow Research using a quantitative permission-based online panel of 2,505 Australian adults aged 18 years and over. To ensure the survey is representative of the Australian adult population quotas were set for gender, age, state and region (metro / rural and regional areas). This sample size gives a confidence level of plus or minus 2% at the 95% confidence interval.

The advantage of a survey of this sample size is that it has been able to include carers and consumers, which has permitted meaningful comparisons between carers, consumers and people who are not carers or consumers. This has allowed for reliable insight to be gained on how carers and consumers view various aspects of managing mental health conditions.

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The **human mind** is a wonderful – and **wonderfully complex** – part of our body

Mental illnesses like schizophrenia and bipolar disorder have been described, albeit under different names, since the earliest days of history. Yet we still don't have a complete understanding about the causes and we are only now beginning to gain clear ideas on the most effective methods of treatment for these illnesses.

Schizophrenia can be broadly defined as a cluster of illnesses with common symptoms including perceptual disturbances (for example, hallucinations), impaired thinking – or 'delusions' – and diminished awareness of being disabled by these features.

There is continuing debate about how many people suffer from schizophrenia. It affects approximately one in every one hundred people worldwide but interestingly, some populations have a higher incidence. Others, for example the Amish communities of the United States, experience near-zero rates of schizophrenia.¹

All sorts of misbeliefs once surrounded the causes of schizophrenia – everything from genes and poor parenting through to poverty.² We now know that mental illness is a combination of genetic make-up, a person's emotional experiences and social factors.³ However no single cause for schizophrenia has been identified to date.⁴

Clearly, the medical and scientific communities have come a long way in regards to understanding and treating mental illness and in particular schizophrenia.

'But there is still much work to be done'.

This edition of the Pfizer Health Report explores some of the attitudes and views of the Australian community towards people with mental illness, and compares these findings with the experience of people who suffer from schizophrenia and bipolar disorder alongside their carers.

It is a vital step in bringing these groups together for a greater understanding of mental illness – what it is, how it affects a person's life and what can be done to help all of us live together as a community where we respect one another's differences.

I commend the Pfizer Health Report to you for thought and action.

The Hon **Judge Frank Walker QC**
Vice President – Mental Illness Fellowship of Australia

Schizophrenia & Bipolar disorder explained



The term schizophrenia is often misunderstood as meaning a split personality. In fact, the term is used to describe the split between reality and unreality for the person experiencing this disorder.⁵

Broadly, schizophrenia is a condition characterised by disturbances in a person's thoughts, perceptions, emotions and behaviour. It affects approximately one in every hundred people worldwide and the first onset commonly occurs in adolescence or early adulthood.⁶

Bipolar disorder is characterised by mood disturbances alternating between mania and depression. It may be difficult to distinguish from schizophrenia as it shares a number of common symptoms including delusional thinking, irritability, agitation and rapid speech.⁷

Causes of schizophrenia

No single cause of schizophrenia has been identified to date. There are a number of possible causes of schizophrenia – from genetic and environmental (including stress and trauma) through to biochemical imbalances in the brain. Some research suggests that substance misuse may be a factor in the cause of schizophrenia though it is also likely that substance misuse may precipitate or worsen already existing symptoms.⁸

A number of symptoms characterise schizophrenia though these vary widely between individuals. Disorganised thinking and behaviour, delusions and hallucinations are described as 'positive' symptoms. Other, 'negative' symptoms include poverty of speech, loss of feeling and withdrawal.⁹

Media publicity about frightening and bizarre crimes has left the public with the impression that most people with schizophrenia are violent. In fact, most people with schizophrenia are not violent and pose no threat of harm to others. To the contrary, they actually account for an insignificant proportion of society's violence.¹⁰

People with schizophrenia may once have been described as 'patients' or 'sufferers'. Today, the term 'consumers' is broadly accepted as a de-stigmatising reference to a person making use of mental health services – including those with schizophrenia.¹¹



CHANGING PERCEPTIONS

The last four years have seen a slow but steady improvement in community perceptions of schizophrenia.



Pfizer's latest (October 2010) research on perceptions about schizophrenia follows an earlier survey conducted in 2006. Comparing the results of the two surveys, it's clear that there have been noteworthy shifts in some community attitudes.

In 2010:

30%

of respondents did not know the incidence of schizophrenia – being the number of cases of schizophrenia present in a given population. This compares to a 'don't know' response of 37% in 2006.¹²

17%

of respondents didn't know the best place for people with schizophrenia to reside. This compares to a 'don't know' response of 27% in 2006.¹³

26%

of respondents didn't know the risk factors for schizophrenia – a significant decrease on the 34% of respondents who couldn't nominate risk factors in 2006.¹⁴

Rob Ramjan, CEO of Schizophrenia Fellowship of NSW (SFNSW) points to a number of factors that have helped to change community perceptions of schizophrenia.

He says, "Over recent years there has been a lot of grassroots advocacy from both carers and consumers. They have stood up in the media and 'had their say'. This has seen the media in general become better informed


and more responsible and empathic in the reporting of mental health issues."

Ramjan adds, "The issue of mental health has also entered the political arena, with in some cases, politicians from both major political parties recognising the need for action in this area. This has further enhanced community perceptions and understanding of schizophrenia."



How we view Bipolar Disorder

Australians are broadly aware of bipolar disorder however insight is limited and there is room for further education.¹⁵



As a guide to community perceptions, 74% of Pfizer's recent survey respondents think people with bipolar disorder have a mental illness. Sixty-nine per cent (69%) see bipolar disorder as characterised by mood swings and a further 68% believe the condition relates to a chemical imbalance of the brain.¹⁶

However consumers and carers are less likely to view bipolar disorder as a mental illness, and consumers are the least likely to believe it involves mood swings.¹⁷

The vast majority of Australians believe bipolar disorder is disabling – only five percent (5%) say it is not disabling.¹⁸ Despite these strong perceptions, 50% of the community believe the condition can be self-managed.¹⁹

Rob Ramjan, CEO of Schizophrenia Fellowship of NSW (SFNSW) says, "Most people are aware of bipolar disorder and many can relate to the problem as we all tend to experience emotional highs and lows."

He adds, "People often have different perceptions of bipolar disorder compared to schizophrenia. This probably dates back to Hollywood-style movies that present schizophrenia as a scary illness. Bipolar disorder has rarely, if ever, featured in horror movies so it's free from the (incorrect) connotations associated with violence that people often think is part of schizophrenia."

Quality Use of Medicine a two-sided coin

Today's medicines offer *fresh hope* for people with mental illness.

According to the Commonwealth Department of Health and Ageing, quality use of medicines (QUM) involves improving health outcomes by selecting management options wisely, choosing suitable medicines if a medicine is considered necessary, and using medicines effectively and safely.²⁰

Pfizer's research found that 74% of the community believes schizophrenia can be treated through the use of medicine²¹ in conjunction with the following associated forms of support:

- Ongoing support from a health care professional such as mental health nurses – **80%** of respondents
- Ongoing support from community – **72%**
- Sessions with a psychiatrist – **68%**
- Early intervention – **66%**²²

Consumers hold very different views about medicine. Fifty-nine percent (59%) are currently taking medicine²³ though only 49% support medicine as a means of treating schizophrenia.²⁴ Sixty-one per cent (61%) believe ongoing support from a health professional or psychiatrist (47%) would be an effective means of treating schizophrenia.²⁴

"Medicine plays a critical role in the treatment of schizophrenia" says Rob Ramjan, CEO of Schizophrenia Fellowship of NSW (SFNSW). "However it's only 20% of the solution. The remaining 80% is comprised of psychosocial rehabilitation and case work."



Medicine forms the bedrock



"Medicines for schizophrenia now have a broader range of potentially beneficial actions than they did in the past."

Professor Tim Lambert, Professor of Psychiatry, University of Sydney

He explains, "The goal of treatment is to manage multiple dimensions of disability associated with the illness.

A well-chosen medicine forms the bedrock upon which psychosocial treatments can be built. Like the building of a house, if the foundations are not strong, the house will sooner or later fall apart. Antipsychotic medicines, when tailored to an individual's particular needs, are like the foundations. The more regularly they are taken, the firmer the foundation."

However as Professor Lambert points out, "People don't live in their foundations, they live in their home – this could represent the psychosocial treatments which actually provide the building blocks and materials of recovery. One can't really have one without the other – optimal medicine accompanied by a selective and appropriate psychosocial treatment plan can deliver excellent outcomes for many people."



NAVIGATING the workplace

The community is supportive of people with mental illness entering the workplace – just as long as it’s not their place of work.

Indicating the extensive support for consumers to gain a place in the workforce, 81% of the community believe that people with schizophrenia want to work.²⁶ However just 57% said they would welcome a consumer in a workplace like their own.²⁷

Community support for employment of people with bipolar disorder is slightly stronger — 84% of respondents believe people with bipolar disorder would want to work.²⁸ Rob Ramjan, CEO of Schizophrenia Fellowship of NSW (SFNSW), says “The community reaction recorded in

Pfizer’s survey is not unusual, and concerns about working alongside people with schizophrenia are usually based on unfounded fears that consumers could become violent in the work environment.”

“The SFNSW runs a number of programs that encourage employers to offer work opportunities to people with mental health issues. It can take some convincing but we typically find that once hired, employers are eager to hold onto consumers – they often prove to be outstanding workers”, adds Ramjan.

“Moreover, people with mental illnesses often flourish when given opportunities to enjoy meaningful employment. It provides a boost to self esteem that can help with their condition, and the income earned from the workforce enhances the opportunity to enjoy the things all Australians want from life, including independence and a home of their own.”

Rob Ramjan, CEO of Schizophrenia Fellowship of NSW (SFNSW)



a ROOF over our HEADS



The community may regard the family home as the best housing option for people with schizophrenia but carers and consumers disagree.

Overall, 41 % of respondents believe the ‘family home’, rather than a separate home owned or rented by the consumer, is the best housing option for people with schizophrenia. Nineteen per cent (19 %) believe being in a home the consumer owns is the best housing option. On the other hand, 14 % say consumers should live in an institution, and indicating the uncertainty regarding this issue, 17 % of respondents ‘don’t know’ which is the most appropriate housing.²⁹

Among carers, only 28 % say the family home is the best place for people with schizophrenia to live – a figure that falls to 25 % for consumers.³⁰

In terms of housing arrangements seen as typical for people with schizophrenia, consumers indicate a variety of options, not just the family home. Twenty-one per cent (21 %) of consumers nominate public housing³¹, and 12 % say a hospital or institution is the typical form of housing.³²

“The reality is that people with mental illnesses are living

in the community more than ever before, and like all Australians, most simply want a place to call their own”, says Rob Ramjan, CEO of Schizophrenia Fellowship of NSW (SFNSW).

Ramjan adds, “There is no definitive research that shows exactly where people with a mental illness are living but in New South Wales many consumers receive support from the state Department of Housing.” He notes, “It can be difficult to gather exact figures on housing arrangements for people with mental illness. While we know that many consumers receive support from the New South Wales Department of Housing, there is evidence suggesting as many as 75 % of homeless people in Sydney have at least one mental illness.³³ We’re also concerned to note research indicating that the proportion of people in NSW prisons with ‘any psychiatric disorders’ is substantially higher, at 74 %, than the proportion in the general population, which is 22 %.”³⁴

Government financial support supportive OR “too hard”?

Pfizer’s research indicates that 19 % of carers are currently receiving a Centrelink benefit and 31 % of consumers receive a disability benefit.³⁵

Half of those carers and consumers who have filled in a Centrelink form found the paperwork easy and about the same proportion found it hard; this strongly suggests there is a large part of this population who find the Centrelink forms challenging.³⁶ Indeed, 17 % of carers say they would like to receive a carer’s benefit but believe it is too hard to comply with Centrelink requirements.³⁷

Rob Ramjan, CEO of Schizophrenia Fellowship of NSW (SFNSW) says part of the problem is that “Centrelink forms are not tailored to mental health issues – they can be quite threatening for consumers and carers. Moreover, physical and intellectual disabilities are often measurable but this may not be the case with mental illness and so there can be little empathy for people with psychiatric disabilities.”

Compounding the situation, Ramjan notes, “Some people with a mental illness are actually forced out of the system by their own illness. They refuse to accept Centrelink benefits because they believe ‘there’s nothing wrong with me’.”

A lack of financial support can be devastating. Ramjan explains, “People with a mental illness may not have the capability to manage personal finances, so income support intended to last a fortnight may only last five or six days before it is exhausted. When this happens, some consumers rely on the support of carers. Others, who don’t have this back up, may have little choice beyond resorting to crime or suffer severe deprivation which will further exacerbate their condition.”

CO-MORBIDITIES

compounding the challenges



Co-morbidities – conditions that co-exist with a primary condition – often affect people with mental health problems, potentially compounding the challenges faced by consumers.

Rob Ramjan, CEO of Schizophrenia Fellowship of NSW (SFNSW) notes certain co-morbidities are associated with schizophrenia. In particular it has been estimated that almost one in five (19%) people with psychosis develop diabetes, compared with 7.5% of the general population.³⁸

When it comes to awareness of potential co-morbidities, Pfizer's research indicates that 55% of consumers have discussed their long term health, quality of life and the medicine they are taking with their mental health care professional – however 27% had not.³⁹ Among those taking medicine, 68% of consumers rate the information they received as good, with only 6% saying the information was poor.⁴⁰

Consumers are generally comfortable (69%) about discussing the best way to improve their quality of life with a health professional⁴¹ and 58% feel well informed about the possible side effects of their medicine. Nonetheless 26% did not feel well informed.⁴²

Professor Tim Lambert, Professor of Psychiatry, University of Sydney says, "Schizophrenia has been described as a life-shortening disease. In terms of co-morbidities this comes about because very many people with schizophrenia die prematurely of cardiovascular disease (heart attacks, stroke, etc)."

He adds, "It is critical for consumers to play an active role in seeking out a health professional who will be aware that the cardiovascular risks that accompany schizophrenia may reduce life expectancy by 15 to 25 years, if not treated. It is not uncommon for mental health consumers to be treated for their psychological problems, but find their physical illness needs neglected as though having one obviates the other."

Professor Lambert concludes, "Consumers need a voice to remind the community that they are receiving a double whammy – mental and physical illnesses that profoundly reduce quality and length of life expectancy. Although there is a global epidemic of obesity and diabetes, patients with psychosis appear to be more prone to developing these problems. The key issues are to think about diet, how much exercise is taken, whether smoking can be reduced or given up, and how such changes may help reduce the high blood sugar, high blood pressure, and high cholesterol found in about 60% of long term sufferers of psychotic illness. Finally, in some cases the antipsychotic medicine itself may promote the development of risk factors such as obesity and heart disease. In such cases, consumers should explore the option of being prescribed an antipsychotic with lower potential to cause cardiometabolic disturbance."

Care co-ordination – a message of hope

Rob Ramjan, CEO of Schizophrenia Fellowship of NSW (SFNSW) believes that despite the challenges faced by people with mental illness, there is also much to celebrate.

“In the area of mental health, one of the key breakthroughs has been the recognition that consumers should be treated with dignity” explains Ramjan. “Official reforms are also playing a key role, and the federal government’s Mental Health Strategy is giving greater empowerment to consumers and carers.”

Broadly, the National Mental Health Strategy aims to:

- promote the mental health of the Australian community and where possible, prevent the
- development of mental health problems and mental disorders;
- reduce the impact of mental disorders on individuals, families and the community; and
- assure the rights of people with mental illness.⁴³

Ramjan believes, “The aims of initiatives such as this reform and Pfizer’s survey is to better inform the Australian community on the importance of mental health and encourage understanding and tolerance of mental illness.”

“We’ve seen impressive leaps forward in terms of community education”, adds Ramjan. “The NSW police force for instance has established a mental health intervention team, with the aim of training 10% of frontline officers in mental health issues by 2015. Changes to Medicare allow general practitioners to spend more time with patients experiencing mental illness. There is also good work being done by doctors. Many practices now have a mental health division, and a significant proportion of general practitioners have undergone training to become skilled in mental health.”

According to Ramjan, “The hope now is for a breakthrough in terms of treatment. In the 2007 National Survey of Mental Health and Wellbeing of Adults (SMHWB), which is based on diagnostic criteria rather than self report, one in five adults (20%) had a mental disorder at some time during the twelve months prior to the survey⁴⁴. Our capacity to improve treatment and the lives of consumers and carers is now greater than it has ever been – there is definitely a great deal of hope in this field.”

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