

CONCURRENT SPEECHES

THE EXPERIENCE OF MENTAL ILLNESS

Abstract:

In this joint presentation, Fred and Penny Frese review the implications for family life when one or more of the members has a serious mental illness. Recent developments in research on genetics, and improvement in treatment and family education increase the likelihood for a successful family relationship. A brief history of stigma, along with practical coping mechanisms for couples and their families will also be discussed.

FRED J. FRESE III

Former Director of Psychology, Western Reserve Psychiatric Hospital

About forty years ago I graduated from college and entered the U.S. Marine Corps. The U.S. Navy had supported my university education and I was obligated to serve in the armed forces for some four years. After my indoctrination training, my first two tours of duty in the military were at bases on Okinawa and in Iwa Kuni, Japan. As you may know, Iwa Kuni is located close to Hiroshima. While at that base, I secured an evening job teaching English to employees of Mitsui Polychemical Corporation twice each week. The Company was located nearby in Hiroshima Prefecture. As a result of my teaching activity, many of the Japanese persons that I met turned out to have lost a mother, brother, or other close family member in the tragic explosion of August 6, 1945.

When time came for me to leave Japan, I found I was being given duties as a guard officer at a Naval base in the state of Florida. There my duties were to oversee security of the brig (jail), a major intelligence centre, and a large storage area for atomic weapons.

The war in Viet Nam had just begun to become a major conflict. I took my duties very seriously. About six months into my assignment I came to realize that something was not right. It seemed to me that certain important persons in America, high ranking military officers, elected officials, etc., were behaving strangely. I began to suspect that their behaviour might become a threat to the security of the nuclear weapons I was assigned to protect. Suddenly I realized that these high ranking people must have been hypnotized or somehow brain-washed by the enemy, maybe by the Chinese Army when they perhaps had been captured during the Korean War. Indeed I quickly became quite confident that these persons were under hypnotic control of the enemy.

I, of course wanted to share this discovery of mine with the U.S. Government. I reasoned that the government official likely to know most about hypnosis would be the Base psychiatrist. I called him up and he agreed to see me right away. When I arrived at the Base hospital I revealed my discovery to the psychiatrist during a thirty-minute chat. The psychiatrist listened politely, even appreciatively. But when I got up to leave, I found that there were two large gentlemen in white coats positioned right behind me. I was not going to be allowed to leave the hospital. I was escorted to the psychiatric ward and put immediately into a small, padded, seclusion room.

In my mind I quickly realized that I had made a serious mistake. Obviously, the psychiatrist I had been talking to was under the control of the enemy. And now the enemy would know that I had discovered their secret psychological weapon, and I became quite convinced that they would quickly attempt to eliminate me. I was terrified. Within a day or so I was able to quickly glance at my hospital record. I learned that I had been diagnosed with paranoid schizophrenia. Initially I was shocked. I had been working so diligently as a security officer, and now I was being labelled insane. Rapidly, however I came to understand that this "schizophrenia" label that the hospital was giving me was just a device to protect me, so that the enemy would think that I was insane and would not feel they would have to eliminate me. They would probably think that nobody was going to believe an insane person. All I had to do was to pretend that I was schizophrenic for a few months.

So for the next five months or so I took the Thorazine and Stelazine. The side effects were terrible. They had no medicine for side effects in 1966. In my mind, there was nothing wrong with me, of course. I was just a Marine Corps security officer doing my duty. And I was rather certain that my discovery of the enemy's psychological, hypnotizing weapon had greatly helped in the war effort.

This telling of my first breakdown describes a little about how I first experienced schizophrenia, but it is not a good vehicle for describing how the mind goes from Aristotelian reasoning and common sense into psychosis. I think that a description of my next breakdown is perhaps more revealing in this regard. Upon being released from the hospital and from the military service, I thought it best that I return to school. I had liked Japan very much and I had learned a little Japanese language while overseas. I decided to study international business. By the time I graduated I had received eight job offers from fairly prestigious businesses and other international organizations. All but one company asked me to fill out application forms, which invariably inquired about my health history, including questions about any psychiatric condition I might have. I took the job with the company that did not ask about my health background.

I began as a management trainee for the Fortune 500 capital goods manufacturing firm, Koehring Incorporated of Milwaukee. In that I knew a little Japanese I was also assigned liaison responsibilities for executives from Ishikawajima Harima, a very large Japanese manufacturer of capital goods. My Japanese language skills were most elementary. I generally could not understand what was being said to me by the Japanese executives. But I did remember that Japanese people seem to be somewhat superstitious regarding the number, four. They often do not have fourth floors in hotels, or a fourth row on planes. This seems to be similar to American's superstitions concerning the number thirteen. While the Japanese seem to avoid saying the number four (shi) which sounds like death, they do seem to particularly like the preceding number, three. Large Japanese firms have names like Mitsui (three wells), Mitsubishi (three diamonds), and Mitsukoshi (three

crossings). Sanwa, Sanyo, and Sansui are other large Japanese firms with "san", another word for three, in their names. Trust me the Japanese seem to like the number three and avoid the number four.

Knowing about their feelings about these numbers, in my conversation with the Japanese visitors I would try to avoid saying the number four and maximally use the number three. For instance, if a contract were to be for about four million dollars, I would say the cost would be between three and five million. (Does anyone see the beginning of psychosis developing here yet?)

Initially I was quite successful. Our Japanese visitors seemed to appreciate my thoughtfulness in respecting their custom. I was assigned to accompany them as they toured the country. I began being invited to have dinner with the company's international vice president. Things were going very well.

One Sunday morning, I began thinking that if I could have such success just by being respectful of the Japanese custom regarding the numbers 'three' and 'four', perhaps I could find a similar number that westerners had feelings about. I remember looking out my window from my Holiday Inn room and viewing the city outline of Milwaukee. The horizon was punctuated with church steeples, many of them with crosses atop them. Suddenly it came to me that America, and most of the West, was built on a Judean-Christian cultural foundation and that all those church steeples were atop "temples to the Trinity". Indeed many of the churches had names like, Trinity Lutheran, Holy Trinity Episcopal, and Church of the Trinity. Trinity, of course stood for "three". Suddenly I realized that so much of our western, American culture was structured on three-ness. The government has three branches, the executive, the legislative, and the judiciary. And it has three levels, the Federal, State, and Local. The colours of the American flag are three, red, white, and blue. The major sources of our news, the radio and TV stations, ABC, CBS, and NBC, all had three letters. And as I looked down below at the traffic flow, I realized that even our very movements, as in the traffic, were controlled by those three traffic lights. On red, the colour of blood, everything stopped. On green, the colour of trees, everything goes, and on yellow, the colour of gold, everything speeds up. Clearly we westerners are influenced by the power of three just as are our Japanese friends. I truly had uncovered a device for bridging from the East to the West. All I had to do was recognize the power and influence of three as our worlds increasingly interacted.

It being Sunday morning, when I was accustomed to going to church, I of course decided to go the largest Temple to the Tri-ni-ty I could find in Mil-wau-kee. I knew where it was. I was in the Holiday Inn on the corner of 7th Street and Wis-con-sin Av-e-nue. I walked up Wis-con-sin to Tenth Street. There in front of me, on the left, were three churches. The first two were protestant churches, Presbyterian and Anglican. The third church, located on the corner of the Jesuit's Marquette University, just where Wisconsin met Twelfth Street, was the very large, red brick, Gesu Cathedral. I entered the building and sat in the back. A service was being conducted. After a short time, I felt myself proceeding to the altar, where the priest was conducting the service. I knew what I was doing was strange, but I also knew I had a new discovery about the importance of three-ness. Because I was beginning to worry about my own stability, I quickly ran through in my head the questions to see if I were oriented in three spheres (Psychiatrists use these as an aid to determine contact with reality). First, Who was I? Answer: Frederick... Joseph... Frese...III.

Second: Where was I? Answer: In the greatest temple to the Trinity in Mil-wau-kee, Wis-con-sin, U...S...A... And what is the time? My discovery was of monumental importance. It was important not just for a few moments or days or even years. My discovery was of cosmological importance. I was at a point in evolution (evil-ution). If I continue to go forward I will be going with evil-ution. I could not go that way. On the other hand, if I went back, I would be going with devolution (devil-ution). I would not go with the devil either. I was at a balance point for the universe. I could not move without moving with evil or with the devil.

Then I began to feel myself becoming like an ape. I began grunting. I then turned into some kind of wolf, like a werewolf, howling, as if toward the moon. Then I became like a dragon. I could feel the heat of the fiery air being expelled from my nostrils. Next, I was like a snake, writhing on the ground around the altar. I then became like a fish, out of water, flapping frantically. Then I was just a one-celled animal, like an amoeba, oozing into the rug. Next I became just a molecule, then just an atom (or was I Adam, the first man). At any rate, I knew if I had become the simplest atom, that of hydrogen, I had to be its third isotope, which is called tritium. And I knew what tritium was for. Tritium was the Atom in the centre of a thermo-nuclear weapon. I had become this atom and I was going to be split (schiz in Greek) and in being split I was becoming the instrument that was being used to bring about Armageddon, the Apocalypse, the ultimate Holocaust. I could feel myself being loaded into a large bomber airplane (later I realized it had been an ambulance). Then all went blank.

When I came to, everything I saw was white. I assumed I was in heaven or perhaps in Limbo. Then I realized I was strapped down to a bed in a small room. I was very thirsty. I began yelling for water. When the water finally came I was told that I was in a psychiatric unit. I remained there, floridly psychotic for a few weeks. Shortly after being released I began a period of over a year in which I was repeatedly re-hospitalized and released. On Independence Day (July 4) weekend, 1968, I was picked up in the streets by the police and taken to the Columbus (Ohio) State Hospital. There after spending a three-day period naked in a back ward seclusion room without a toilet, I was cleaned up, taken to a court and officially determined to be an insane persons under the laws of the state. I was told I had a deteriorating brain disease called schizophrenia and that I would probably spend the rest of my life under the care of state psychiatric hospitals... That was not a real good day for me.

I was finally released from the hospital. Somehow, after a few months, I was able to find employment, working in a maximum-security psychiatric hospital. I was instructed to tell no one about my psychiatric condition. After three years working as a "mental health professional", I returned to graduate school. Despite two additional hospitalizations, I was able to earn masters and doctoral degrees in psychology. I then returned to work in the state psychiatric hospital system. In a short period of time I was promoted to be the Director of Psychology at what was then Ohio's largest psychiatric hospital. This was just twelve years after I had been committed to this hospital system as an insane person.

Until the mid 1980's I kept very quiet about my psychiatric history. Frankly, the topic seemed to be somehow taboo. No one wanted to talk or hear about it. There were mental patients, of course. At the hospital there were hundreds of them around us every day. But they were different from the rest of us. They were mentally ill. We were assumed to be normal. The idea that one of them could become one of us was, in a word, unthinkable. No one thought such a thing would ever happen. No one seemed to consider what would happen to mental patients if they were to get better, but clearly they would never become one of "us".

In 1985, however, I happened to attend a local meeting of the National Alliance for the Mentally Ill (NAMI). I was astonished with what I observed there. After twenty years as a diagnosed schizophrenic, never running into another recovered (or recovering) person, and only rarely meeting families that would acknowledge that they had an “insane member in the family”, I found a room full of people who were most open about their family members’ condition. I found the experience most refreshing. Shortly after attending a few meetings I was approached about serving as a consumer representative on the local community mental health funding board. I accepted the appointment, and initially served discreetly as the first consumer member of that Board. Actually I was somewhat amazed at how discreet the board members and staff were about my condition. After a while I decided to become significantly less discreet about my psychiatric history. Indeed I began giving speeches, such as the one I am giving today in which I openly identify myself as a person in recovery from serious mental illness.

Quite frankly, the past fifteen years during which I have been invited to give hundreds of speeches in over forty-five states, half the Canadian provinces and several Japanese prefectures have been a real adventure for me. Numerous very important developments have occurred and I feel most fortunate to be part of what are beginning to be major changes on how seriously mentally ill persons are treated and perceived by society, or those I have come to call, the chronically normal people (CNP’s). Succinctly, I see the world of care of the mentally ill rapidly changing from a professional-, hospital- or community-based system to a consumer- and family- driven system, the components of which are a major focus of this conference.

During the past two decades we have seen many important changes for the mentally ill. We have seen psychiatrists, psychologists, and other professionals beginning to take a more serious interest in serious mental illnesses. We have seen the development of much better medications and other treatments. In the U.S we are beginning to see implementation of both evidence-based-practices and the increasing influence of the recovery model. We are experiencing consumer and family involvement in development and implementation of mental illness research efforts. We are seeing the establishment of mental health courts and specialized mental health police training. We are seeing increasing numbers of consumer run businesses and peer-support operations. And we are uncovering so much about the biochemical and genetic aspects of these illnesses.

One of the most cited graphs referring to the heritability of schizophrenia is that of Irving Gottesman. This graph shows the correlations between degree of family relationship and likelihood of coming down with schizophrenia. Obviously members of families that carry the gene for schizophrenia have heightened likelihoods of passing the vulnerability for this condition on to their children and grandchildren.

The work we consumers and families have been doing is making life better not just for our current living family members but also for our children and for generations to come. Our children have all inherited some degree of mental illness and take medicine for their conditions. A few years ago we found ourselves on the front page of the market section of the Wall Street Journal. That was really good because that meant that that year we did not have to send out nearly so many holiday cards.

You have heard now about my illness from my perspective. I would like now to present my wife, Penny, who will tell you more about what living with these conditions has meant for her and for our children.

PENNY FRESE

Past-president Summit County Mental Health Association

Like most people, I grew up knowing almost nothing about mental illness. No one I knew was mentally ill although I had heard my parents speak in hushed tones about some distant relative who had to go to the hospital for a while and how sad it was. His wife had divorced him. There was a man in my neighbourhood who wore several coats in the heat of summer and talked aloud to himself. When we children saw him outside, we crossed the street and then secretly made fun of him. That was what I knew.

Fred and I met in graduate school the spring before my final year. He was on the science side of campus and I was on the art side. We became friends over the summer when most of the students had gone home and we stayed on to work on our dissertation proposals. I admired his intellect, his “vacuum cleaner mind”, his deep faith, and his wonderful sense of humour. I could speak to him about anything and he seemed to understand.

It was in the fall, just before the new school year resumed again when I learned Fred’s secret. In some ways I forced it from him. I had noticed that he never spoke of personal things and someone had warned me darkly that he was divorced. It seemed strange to me that he never mentioned this and I was suspicious about his intentions in our relationship. When I asked him why he never got personal, he agreed to tell me about his life the following day. So the next day we went for a walk in the forest, which surrounded our campus. When we had walked about an hour, Fred began his story with a deep sigh. He told me that at the age of 26, as a Marine Corps officer, he had had a breakdown and had been diagnosed with schizophrenia. Other breakdowns had followed, and he still wrestled with the illness. His marriage had failed because his wife was also diagnosed with schizophrenia. There had been a child, a little girl.

This was not what I had expected to hear. After the word “schizophrenia” everything got blurred. My heart pounded and I felt like I could not breathe. All I could think was “I have just walked for an hour into the woods with a man who is telling me he is insane. Oh, God, get me out of these woods alive!”

That was 25 years ago. We are still very much alive, but I am not yet sure that we are out of the woods. Fred and I were married in the spring of the next year. But I still had a lot to learn; in fact 25 years later I am still learning. Coming to terms with mental illness in our lives has been a process. I suspect every family who must cope with this illness goes through a similar one. I would like to share with you some things about that process so far. You may find they resonate with your own experience. Or that you have some insights to share that I have not yet attained.

Like many people my first response to Fred's illness was denial. Of course, I could not deny that he was diagnosed with the illness. That had happened ten years before and it continued to give him problems. I entered into another stage of denial: bargaining. I thought that perhaps if I was as good a wife as I could be; if I was loving and faithful, supportive and did not complain, that God would take this illness away. I did my best and it took me about two years to realize that the bargain had never been struck. I did my part, I thought, and the illness remained, and I was not very happy about it.

When Fred developed his aspects of coping, he listed denial as the first aspect. When he showed this, I told him that I did not think denial was a way of coping. "Yes, it is," he told me. I have come to understand that denial is for many of us our first response, our first coping mechanism. It is not a good one, but it is often the first. There are many reasons for this. Mental illnesses are long term. For years, families have been blamed for "causing" the illness. There was little hope for recovery. Surely, our loved one, our family member could not be mentally ill. It must be something else—lack of will power, a character flaw. We are good people, why would this happen to us?

Not only families try to cope by denying. Whole peoples shun the need to deal with mental illness. We hide the mentally ill away in institutions where we cannot see them, and when we cannot hide them away, we turn away as we walk by them in the street. We exclude them from medical insurance; we cut their services when the economy is poor. We cannot talk about it, and if we do talk about it, we blame someone else for their condition. Unfortunately, we are learning the tragic, and sometimes deadly, consequences of our failure to face these illnesses, especially in our children.

Eventually, I had to face the reality that there was mental illness in my family, it was not going away, and I was going to have to deal with it. That was the beginning of my recovery. Because I am an old teacher, I must break down the aspects of my learning to cope into three parts—what I call the three A's. Acceptance, Accommodation, and Advocacy. They do not necessarily occur one after the other, but I must speak of them in this fashion.

First, I had to answer the question: Why do bad things happen to good people? The answer, of course, is: Why not? Who better for bad things to happen to than good people, because good people take bad things and bring good from them.

Acceptance for me came in two stages. The first stage, acceptance with a small "a", was finally agreeing that mental illness was going to be a part of our lives and I would have to make some room for it. I didn't do this very well; I wanted to give it only a little corner of my life. "Take your medicine, look as normal as possible, and please try not to have an episode on Tuesday or Thursday nights when I teach!" No matter, it was a start. I knew that we had a dragon in our living room, and I would have to make peace with it. Part of that was learning as much as I could. In those days there was not too much material available, and apart from our families and my husband's employer, no one could know. Today there is much material written for the general public and family support groups all around the world who often offer educational programs as well. I was very fortunate that my husband was a mental health professional and became my teacher and support, especially as our four children, one by one, began to be diagnosed with major depression. I also had to learn that "the perfect life" was a myth, created by the advertising industry and promoted by mass media. I could live a good life, happy and fulfilled, even if it had more than its share of sorrow and pain; and maybe *because* it had more than its share of sorrow and pain.

Eventually, I learned acceptance with a large "A", that is, acceptance of my family members *with* their illness. It is a part of who they are, and it is ok. I have come to see that these illnesses come with their own special gifts. I have seen these illnesses cut rivers of compassion and patience in my children. As a family, we enjoy our own special kind of zany humour, a kind of creative elegant absurdity that we find very funny, but which, my children tell me, escapes many people. Humour has enabled us to find relief from many stressful, difficult situations. However, Acceptance with a capital "A" does not mean that I want to trivialize or romanticize this illness. It can be demanding and ugly.

I am not glad that my family members suffer from it; I still wish it would go away. Acceptance does not mean that abusive, threatening, or dangerous behaviour can ever be tolerated. But acceptance with a capital A does mean that I am willing to do what I must to create an environment that is healthy, supportive, and loving. I will not ask someone else such as the doctor, therapist, social worker, or medicine to do what only I can do; that is, to be a spouse or parent to someone who is ill. I will not give in to self-pity. We have a saying: "What doesn't kill you, makes you stronger," but Fred likes to say "What doesn't kill you can really, really hurt." Everyone in this movement knows what it is to hurt; we eat pain for breakfast! Mental illness is not for weaklings; if you are not strong when mental illness strikes; it will make you strong—or kill you.

Acceptance with a capital "A" means that I will also ask such courage from my loved ones. They are the ones who must learn to manage their illness. Despite their illness, they must live in this world, find happiness, fulfillment, and make a contribution. Mental illness may be the reason for their difficulties, but it can never be an excuse. They are the only ones who can take responsibility for their lives. They must find their own way. I tell my children that even if I wanted to, I cannot take this responsibility from them, nor can they give it to me. But Acceptance means that I will companion them on this difficult journey. I will cry with them when they are in pain and celebrate their victories.

Accommodations are the little tricks we learn to avoid problems and make our lives easier. We make accommodations every day. For example, if we know that a certain subject is unpleasant for someone, we avoid it. Accommodations are often just that kind of common sense. They are very practical, suited to the individual symptom, and are made both by those of us who are well and those who are ill.

To be able to make an accommodation, we first must be able to recognize behaviours that are symptoms of the illness. Recognizing behaviours as symptoms is important, because it helps us to separate them from our own feelings and deal with them more objectively. Here are some of the symptoms I have noticed in my family:

Interior absorption: this means that certain ideas, worries, or feelings become so demanding that they block out all other considerations. They may make it hard to focus, concentrate, work, or attend to other things. Confusion or frustration may be the result.

Tangential thinking: Because our loved ones often over-connect ideas, they may appear to us to be off the topic. We cannot follow their rapid connections. Decision making in such situations can be difficult, because all options seem of equal value.

Sleep problems: it is not clear if these are related to the illness, the medications, or both. My children cannot fall asleep, cannot stay asleep, and cannot wake up once they are asleep. They report being overwhelmingly tired, even when they have slept for a long time. The onset of sleep problems is one of the sure signs that they are relapsing.

Irritability: the struggle to concentrate; appear normal; fight fatigue, anxiety, or distractions can wear down my children's capacity to bounce back. When they are home or in another comfortable place, they are sometimes be at their worst, where they feel safe to explode.

Exquisite sensitivity: researchers have noticed increased receptors in the brains of persons with schizophrenia. Brain structure or chemistry may account for the increased creativity, and intelligence that is often found among those prone to mental illness. It may also account for their increased sensitivity to rejection, danger, insults, or injury.

Failure to make eye contact: this can be a way of focusing. Looking at someone directly may yield too much information; looking away allows them to concentrate on what is being said.

Reactions to medications such as weight gain, akathisia—what we call “the walkies,” the inability to sit still.

Anosognosia: the inability to know that you have an illness. Although it resembles denial, it is not the same. When well people are in denial it is often because they do not wish to face the stigma or the prospects of a long-term, demanding illness. But persons with mental illness often have impaired ability to understand that what they are experiencing is the result of a brain malfunction. John Nash, winner of the Nobel Prize in Economics and schizophrenic, says of his delusions that they came to him in the same way that his prize-winning ideas did. He had no reason to disbelieve them.

Talking aloud. Sometimes this is in response to “voices” or auditory hallucinations. But it may also simply be a result of interior thoughts so strong that the person does not even realize that they are verbalizing them.

There are many other symptoms, some that are very common such as grandiosity, and some very peculiar to the person, such as the belief that one has a specific mission. It has been important to me to understand that accommodations to these symptoms are not always the job of the ill person.

Some symptoms such as talking aloud or having to get up and walk may look a bit odd, but really do no harm. In these cases, those who are well can easily accommodate by expanding the parameters of what they consider normal. While I will give my husband a little nudge when his talking aloud is disturbing to people, like at a restaurant or on the plane; if he wants to shout to himself while outside mowing the grass or taking a shower, no one is bothered.

Low self-esteem often accompanies these illnesses. Remember that many people who become mentally ill are very bright and creative. Everyone expected great things from them, and then all that promise was destroyed by their illness. People with mental illness do not need us to tell them what is wrong with them. What is wrong with them jumps up and hits them in the face everyday. They need to hear what is right with them. They need to be complimented for overcoming difficulties, for getting up in the morning, for managing their temper, for taking their medication faithfully. In our house we have a room that people walked through everyday. On the walls we put up awards, letters of praise, any kind of recognition that was received. It reminded our mentally ill members that they are capable and appreciated, and it was also a reminder to anyone who visited us, that people with mental illness are capable of remarkable accomplishments.

These are a couple of examples of accommodations that well family members can make to help manage mental illness in our lives. If the symptoms of mental illness begin to interfere with someone's ability to function, then the ill person must find accommodations to restore him to a more acceptable state. Irrational anger, for example, presents a serious danger to the ill person and to those around him. He must find a way to protect himself and others. This might mean learning to walk away from upsetting situations; it may be to become skilled in practicing relaxation techniques such as Yoga.

Sometimes the ill and the well person must make accommodations together. Persons who relapse when they work full time or carry too many responsibilities may need to work out a more relaxed or flexible work schedule. Whoever must make a change, we all try to bear in mind that whatever difficulties mental illness may present, there are always options. The willingness to adapt and accommodate is often less difficult and has fewer consequences than rigidity.

Advocacy is the queen of the whole process of coping. Initially, when one is just learning to cope, advocacy seems impossible. I wanted to get away from mental illness, not become more involved in it. That was because I thought advocacy meant doing more. Trying to help my husband, raise my family, arrange for treatment, and hide the fact that anything was wrong left me no time to do more. I now know that advocacy does not necessarily mean doing more; it means doing differently. We can advocate right where we are, with the people we meet everyday by sharing what we know and listening to others stories.

Advocacy allows us to bring good out of this bad experience. As my children became ill, I knew that life would never be better for them unless it was better for all children. I knew that their friends and their teachers needed to know that they were experiencing a brain disorder. I knew that their schools had to have some plan for helping them succeed, and because I understood my children better than anyone, I would have to help with that plan. I could not expect others, who had no experience with mental illness apart from its distortion in the media, to really understand what was going on.

The amazing thing to me was that as I reached out to others, they reached back. Mental illness is a well-kept secret, but when I could talk about it I found out how many people carried the same burden of silence that I did. I became someone they could talk to, but I also found support in them, and as we talked we all became excited about reaching out to others and helping to make the changes we saw were needed if our loved ones were to recover and live satisfying lives.

We found that everyone had a role to play, well and ill members alike. We have encouraged our children to speak frankly with their friends about their condition. Our daughter Claire made a video about her experience with childhood depression that is now used around the world. It encourages children to recognize symptoms in themselves and their friends and to ask for help. And we see that children do—they seek help for themselves and they bring their friends who are having trouble to a caring adult.

Advocacy not only changes unjust and ignorant systems, but it heals those who have been broken by those systems. It validates their suffering and gives them worth. Claire once said: “If I’m going to be talking to others about managing their illness, I had better be managing my own.”

When we advocate, we join forces with millions of people around the world who are working to change the face of mental illness: the doctors, therapists, counsellors, teachers, researchers, pharmacists and chemists, and the millions of family members and consumers who every day are on the front lines of this battle. If each of these groups could have done the job alone, they would have. But individually, they are not enough. Each of us has a little change we can make. Even a little change, like a ripple in a pond can have a far-reaching effect. Twenty-five years ago I was trying to get out of the woods; today I am in Japan talking about it.

Of course it isn’t easy. People resist change. Often, they are not interested, too busy, too entrenched in their habits to want to change. What should we do? I recommend the small dog approach. Bite the ankle; hold on. We know that what we do is right and time is on our side. We know we are not fighting only for ourselves, but for all those who do not yet know they are at risk for these illnesses, for children not yet born. Our family joins with your family so that other families will find the path easier. For myself, my husband, my children, and someday my grandchildren, I thank you for what you are doing and will do to make their lives better.

THE FAMILY MOVEMENT AROUND THE WORLD: SYMPOSIUM A

WFSAD: THE WORLD VOICE FOR FAMILIES OF THE MENTALLY ILL

DIANE FROGGATT

Executive Director

Abstract:

This year marks the 20th anniversary of the founding of WFSAD. Like most NGOs WFSAD had a slow beginning made more laborious by the difficulties of international communication. This talk will trace, through illustration and stories, some of the phenomenal successes WFSAD has had as its influence has increased.

Presentation Overview

- Who We Are
- What We Do
- How We Work
- Worldwide Outreach
- The Problems
- Our Priorities

Who We Are

The World Fellowship for Schizophrenia and Allied Disorders is the world voice for the family on key issues affecting themselves and their loved ones with mental disorders. We work with other global organizations in the field to achieve our goals which are

to increase understanding and education and to reduce fear, anxiety & discrimination against those who suffer and their families.

We could be called “the world family of families” with over 100 organizations as members, 23 of which are National Family Organizations.

We work from the grass roots, helping to support individuals who contact us. Many have nowhere else to turn. We help and advise family self-help groups and organizations of all sizes. We liaise with our members in order to be able to speak with one voice over pressing issues common to us all.

We attempt to educate and inform with every means at our disposal, through pamphlets, booklets, the website and more. The proceedings from our last conference (2000 in Jerusalem) are an example of valuable information for everyone in this area of work.

Many of the national organizations affiliated with us are well established and are excellent resources for others of our members not so well developed. We promote their programs, practices and information and in some cases distribute some of their materials.

What We Do

- We promote the creation and development of family self-help organizations in all parts of the world.
- We provide and encourage the international exchange of information and promote best practice models for treatment, care and recovery.
- We support individuals when there is no help available in their country.

Our second president, Geraldine Marshall, was instrumental in encouraging the beginning and development of the Russian family movement. A national association now exists with many smaller active affiliates.

Through our program Families as Partners in Care we are attempting to promote the use in general clinical psychiatric practice, of a comprehensive approach to care. This approach, well documented with research, shows better outcomes for patients when the families are actively involved, not only with their care but with the professionals who are looking after their relatives.

Our Support Service increasingly provides support, information and advice through the internet for anyone sending an inquiry through our website. Recently we have helped people from Iran, Bangladesh and many other countries. We prefer to try to answer people's questions ourselves and only later referring them to family associations or other sources that might be helpful.

How We Work

- With a Board of ten Directors from different countries.
- Each acts as a field worker for countries in the region.
- Each is an expert in their own right, having served the national organizations in their countries. Some are mental health professionals as well as being family members. Their professions being psychiatric nurse, psychologist, Occupational Therapist, psychiatrist, etc.
- With regular exchanges of ideas and support from our membership
- The Members' Assembly which took place just two days ago is an example of a method of exchanging ideas among the membership.
- With openness of spirit and absence of dogma. Though we hold copyright on all our materials, we allow reproduction freely, so long as the source is recognized. We do not subscribe to one method, one treatment or restrict ourselves in any way. The field we are in is young and there are many miles to go. We remain open to all approaches to care and to research.

Worldwide Outreach/Training

- 2001 Brought Indian family leaders together to build the family movement.
- 2002 Brought Latin American family leaders together for similar purposes.
- Helped to develop the amazing work done in Uganda and Kenya in last five years;
- Enthused and stimulated families in South Africa, the Philippines and elsewhere to become a viable force for change.
- Encouraged respect for the work and expertise of families in caring for their unwell relatives.

What Family Members Say (1)

"In the middle of an important meeting, I would get a call that my sister is threatening to jump off the terrace, and this happened more than once. What could I do? What could I tell my employer? I do not think my Doctor understood this at all? "

A media executive from Mumbai

Imagine the Problems in the Developing World

- Rudimentary mental health system at best.
- Extreme variations in educational level.
- Ignorance that these conditions are medical.
- Lowly position of and prejudice against women.
- Appalling conditions in custodial care.
- Lack of medications & quality control + prohibitive cost.

What Family Members Say (2)

"First of all there is a need to accept the problem as an illness and not as a curse as most of us Indians tend to believe. Thereafter, stand by the patient in all circumstances. For this we need information and guidance."

A caregiver from Delhi

Some Advantages for the Developing World

- **No culture of family blaming or valuing "independence."**
- **Recognition of human frailty and likelihood that disability may befall a family member.**
- **A culture of looking after the more unfortunate.**
- **Rural communities more tolerant of eccentricities.**
- **Better likelihood of limited employment in farming communities.**

What Families Say (3)

"Drugs subside the illness only. Family plays the most important role in recovery- but all members of the family will not be, and cannot be as understanding as the parents are. Sometimes, as parents, we feel that we keep a pet bird in a cage at the inconvenience of others."

A caregiver from Kerala, during the 2001 1st National Meeting of Caregivers in Chennai, India sponsored by WFSAD

Our Priorities

- Timely, appropriate care in appropriate settings.
- Human rights and against stigma.
- Better employment/occupational opportunities.
- Recognition of the rights and value of the family.
- Support from partnerships with professionals.
- Better levels of care taking advantage of newer treatments, models of care, new research.

Some Statistics: Japan

In a city of 3 million (Kyoto) about 15,000 are sick with schizophrenia.
The number of people who will be diagnosed with schizophrenia this year is about 1 in 4,000.
Therefore in Kyoto 750 people will be newly diagnosed this year.
These families need our help! There is much to be done!

The World Fellowship is...

... the only worldwide international organization helping families, friends and people with serious mental illness to work collectively to advocate for better care and treatment for people with these disorders.

The Serenity Prayer

Lord, Grant me the serenity
To accept the things I cannot change,
The courage to change the things I can
And the wisdom to know the difference.

MARTHA PIATIGORSKY

ALIANZA LATINA WFSAD – A SUCCESSFUL BEGINNING

Abstract:

WFSAD recently invited 21 Family Leaders from ten Latin American Family Organizations to Guatemala City to participate in a Symposium and workshops held in conjunction with the 22nd Latin American Congress of Psychiatry. The group, that decided to call itself "ALIANZA LATINA WFSAD", agreed to continue working together for a better quality of life for the families of the mentally ill. It was also agreed to meet again in Caracas, Venezuela in October 2003 at the Regional Congress of the WPA to continue the work. This paper will describe the enthusiasm experienced by the delegates and the positive achievements that are planned as a result. (Ask Martha for her text about Guatemala.)

YOSHIO NOJI

Executive Director, Kyoto Prefectural Family Association

Abstract: The present state of affairs is full of dismay for family members with their loved ones suffering from mental illness. First, parents are becoming more and more aged and exhausted. Second, families lack of knowledge of the symptoms of mental illness, and information about social welfare resources and systems, cause them to give up fighting stigma. They are really tired. Help from any direction would be welcome. Treatment and care necessary for the consumers should go hand in

hand with appropriate social help for the family members, who could play an important role in affecting the outcome. To improve access to care and ensure the highest quality help for the suffering families, administration and local government must be central to the development of policies, programs, and services. Administrative negligence has been serious.

We are not likely to get the full text of this. Diane has some notes.

UGANDA SCHIZOPHRENIA FELLOWSHIP (USF): FIVE YEARS EXISTENCE: SUCCESSES, CHALLENGES AND HOPES FOR THE FUTURE

THOMAS WALUNGUBA

National Chairman USF Butabika

Abstract: This paper describes the five-year history of the Uganda Schizophrenia Fellowship—its successes, challenges and hopes for the future. USF is a non-governmental organization founded in September 1997 with the primary goal of improving the welfare of people suffering from schizophrenia and allied disorders. It is affiliated to WFSAD as a voting member. Membership is open to family members and friends of people suffering from schizophrenia or allied disorders, patients who have improved, mental health workers and anybody who is interested.

INTRODUCTION:

Uganda Schizophrenia Fellowship (USF) is a non-governmental organization founded in September 1997, with the primary goal of improving the welfare of people suffering from Schizophrenia and allied disorders. USF is affiliated to the World Fellowship for Schizophrenia and Allied Disorders as a voting member.

Lay persons, especially those related to people suffering from Schizophrenia, can by working collectively help to ameliorate the problems of Schizophrenia. Some of the problems people with schizophrenia experience include stigma, the inability to speak up in defence of their own rights, the lack of someone at home to encourage him or her to take medication and comply with recall appointments. Lack of affordable psychiatric drugs is also a major problem.

OBJECTIVES OF U.S.F.

Our objectives are to reduce fear, anxiety and discrimination against those who suffer from Schizophrenia and other Allied Disorders; to prepare and disseminate information about Schizophrenia in health education programmes; to encourage and facilitate national exchange of relevant information among lay persons, health professionals and non-governmental organizations that may further the purposes of the Uganda Schizophrenia Fellowship.

MEMBERSHIP:

Membership is open to family members and friends of people suffering from schizophrenia or allied disorders; patients who have improved; mental health workers; and anybody who ascribes to the organization's objectives. USF currently has 112 members.

SUCCESSES:

Over 100 families have been visited both in Jinja and Kampala districts. The organization is able to provide regular supportive counselling to its members. Over 800 health professionals and students have been sensitized through seminars. Members of the public have been sensitized through activities such as participation in the World Mental Health Day celebrations since 1997.

Psychodrama, songs and poetry are presented in schools and churches. We have developed IEC materials, for instance a video about the play entitled "I wish I knew" has been produced. It is used as an educational tool. 120 weekly support meetings have been held in Jinja and 48 monthly support meetings have been held in Kampala. Members of USF conduct health talks at the mental health clinic at Butabika National Referral Hospital regularly. We have also presented talks on different topics in mental illness on the electronic media. A U.S.F Newsletter has been produced twice, and leaflets about schizophrenia have been produced.

A U.S.F Building is under construction at Bugembe Health Centre in Jinja, although it still needs a lot of financial support. We have attained full registration of U.S.F as a non-governmental organization (Reg. No.S.5914/2613.)

U.S.F has been represented at International Conferences on mental health issues in Germany, South Africa, Israel and locally during the World Psychiatric/Uganda Psychiatric Association Conference in Kampala and Nurses' Conference in Mbarara. Mr. Mufumba Emmanuel Co-ordinator U.S.F Jinja Branch participated in a Training Programme in Italy.

Most recently the first ever family training session for parents, relatives, religious leaders, friends and careers of people suffering from severe mental illness, and mental health professionals took place at Community Mental Health Centre Butabika as part of the Families as Partners in Care programme. Psychiatrists are willing to work with families.

CHALLENGES:

Stigma - some of our clients are still not able to openly come out. Uganda in general has a poor communication system and there is a lack of transport. We have limited funds, and in particular we have need of financial support to complete the construction of the U.S.F. building at Bugembe Health Centre, Jinja..

HOPES FOR THE FUTURE:

Future plans include training mental health professionals on how to work with families in caring for people suffering from schizophrenia and allied disorders. We also plan to train more family members, relatives, religious leaders, friends and careers of people suffering from severe mental illness in the Family as Partners in Care program. We will continue with the sensitization campaign and to wage a campaign against stigma. We also need to strengthen networking between families and sister organizations and international

organizations. We also hope to initiate a psychosocial rehabilitation programme for people living with severe mental illness, initially in Jinja and Kampala districts.

Thank you very much for listening to me.

ANTI-STIGMA: SYMPOSIUM B

FIGHTING STIGMA AND DISCRIMINATION BECAUSE OF SCHIZOPHRENIA

PROFESSOR N. SARTORIUS, MD, PHD

Geneva

CYCLES OF STIGMA AND DISCRIMINATION

The vicious circles of stigma: the individual

Marker/label > Loading > Stigma > Discrimination > Disadvantages > Less self-esteem > More disability > Less resistance > marker/label

The vicious cycles of stigma: the family

Shame, guilt and worry > Reduced reserve > Less support to members > Breaking links among members > Increased stress for all > (Re)appearance of stigmatized disease > leading to more shame, guilt and worry.

The vicious cycle of stigma: mental health services

Enhanced stigma > More involuntary adm's and "problem patients" > Poor reputation of service > Little money > Deteriorating facilities > Poor quality staff > Poor staff output > Bad overall service > THUS ENHANCING STIGMA

Characteristics of WPA programme against stigma

- Aiming at targets identified as disturbing by patients, families and health care
- Long term engagement, not a campaign
- Organized in sequence, flexible in timing
- Cascading: those who participate in the programme serve as consultants to those who have just begun doing it
- Multisectoral: the programme involves different professions, different agencies and organizations
- Multicentric: currently involving many sites

The main targets of the programme differ from country to country.

- Some targets have been identified in several countries. They include:
- School children
- The media
- Psychiatrists and other doctors
- Community "agents" e.g. shopkeepers
- Police and the legal profession

Methods used in the programme

- Speakers' bureau
- Education of families, of doctors, of others.
- Regular encounters with the media representatives
- Legal action
- Press releases and ad hoc media events
- Person-to-person persuasion
- Support to the creation of NGO's

Sites of the WPA Programme - Countries in which the programme is underway

- **Africa:** Egypt, Morocco, South Africa
- **Americas:** Brazil, Chile, U.S.A.
- **Asia:** India, Japan
- **Europe:** Austria, Germany, Greece, Italy, Poland, Romania, Slovakia, Spain, UK

Countries in which the WPA programme is starting

- France
- Kenya
- Lebanon
- Lithuania

The programme maintains collaboration with actions against stigma in other countries

Future prospects

- Development of materials that will bring the experience gained to the attention of potential users in various parts of the world
- Creation of regional networks of sites and groups participating in work against stigma
- Expansion of work to cover other mental disorders (and other diseases)

BARBARA HOCKING

Executive Director, SANE Australia

Abstract: This presentation will outline the stigma-reduction activities of SANE Australia, a national charity working for a better life for Australians affected by mental illness. This will include a description of the award winning SANE StigmaWatch program which is based on SANE's website, as well as the ongoing consultancy and developmental work with the mass media.

SANE is a national charity helping people affected by mental illness. Its focus is threefold: campaigning, education and applied research. SANE works **with** and **for** people affected by mental illness in order to reduce stigma and discrimination. SANE works in partnership with consumer and carer groups, but also with Australia's national peak bodies, SANE working in partnership ACROSS, ACROD, and MHCA. Our work also extends to Professional Colleges, Universities, Government departments, Health Promotion agencies, Philanthropic Trusts, the corporate sector, International alliances.

SANE campaigns are designed to end stigma, and work for access to effective treatments, support in the community, and help for family and other carers through its SANE "Charter for a better life for Australians affected by mental illness."

Stigma matters

Stigma has a direct effect on people's mental health, even to suicide and it affects people's ability to get help; it contributes to hopelessness, employment or to study. People with a mental illness, and their families, rate stigma as the number one factor to improve their lives. People with a mental illness and their families experience stigma from both health services and the community.



What is SANE Australia doing to reduce and remove stigma? It is making every attempt to improve mental health literacy through its Stigma Watch. The aims of Stigma Watch are two fold: SANE promotes accurate, respectful and positive reporting of mental illness in the media. SANE works on an ongoing basis with journalists and scriptwriters to improve their general knowledge and understanding of mental illness and its treatment, and to ensure they use correct information in their writing. Several SANE pamphlets explain the various aspects of mental illness.

Part of working with the media is to ensure that the process is adhered to. Reporters must verify their information; they must identify the correct sources (the responsible person or agency involved) before taking action. After the event they must document the follow-up. We have developed an ongoing consultancy with the media. This enables us to work with scriptwriters on TV programs such as 'Home and Away' and 'Stingers'. We regularly place stories and personal profiles of people with experience of mental illness in newspapers and magazines.

SANE also works to improving community attitudes. Recently the Sony Corporation released a game for the latest Play Station. SONY Computer Entertainment. There was a website promotion. The game involved threatening characters 'released from a lunatic asylum'. The user is encouraged to 'take a walk around...their mental anguish and come out screaming for more'. We approached the Sony Corporation, as did the National Alliance for the Mentally Ill in the United States, and the advertising was withdrawn. HAS THE GAME BEEN WITHDRAWN?

Head's Caps, which advertised using and repeating the word 'schizo' in their ad for a baseball cap. Our members and members of the public are asked to inform us of any such insensitivity so that we may pursue a complaint and get redress.

Reducing stigma within health services

There is still much work to be done in this area. Over-worked and under-resourced services are high stigma risk. Systematic change is needed. Health professionals need to be more compassionate and understanding. Health workers seem to have too much on their plate and many forget just how important kindness is.

"They don't realise how worthless they make us feel."

"I took my boyfriend to hospital as he had a psychotic relapse and was distressed. The doctor treated him like he wasn't there. She gave no reassurance about the illness, and was angry about me asking for information. I was extremely frightened as I had no experience."

Understand about the harm stigma causes

Focus on recovery

Learn as much as possible about new treatments

Educate about illness and treatment

Involve families as partners wherever possible

Refer to community accommodation, rehabilitation and recreation programs

Work with local media

SANE Australia's Stigma reduction activities are a part of our core business and are integral to all our activities. They are completely compatible with all our national activities.

DR. SHUNSUKE TAKAGI

(Ueno Clinic)

Member, Renaming Schizophrenia Committee, Japanese Society of Psychiatry and Neurology

CHANGING THE JAPANESE TRANSLATION OF "SCHIZOPHRENIA" AND ITS IMPACT ON STIGMATIZATION

Abstract:

It was back in 1993 that Zenkaren or The National Federation of Families with Mental Illness in Japan first appealed to an authoritative organization for consideration of renaming the Japanese translation of the word schizophrenia. The old nomenclature carried stigma in itself. In August 2002 a new name was recognized as more appropriate. This is a step forward. These past nine years have seen some changes in several fields of mental healthcare policy, but in general, little progress has ever been made in reality. A new law to reduce barriers to better surroundings for consumers has been made. A recommendation was made to implement programs designed to strengthen the capacity of community-based treatment and care. Success will come only through selfless cooperation.

Background of Renaming

Current status and history of social situation of Japanese psychiatry

Image of the name "seishin-bunretsu-byo" \Japanese translation of "schizophrenia"

Symbolic Importance of Movement of Renaming

Japanese Psychiatry Declares Emergence from the Era of Detaining Psychiatric Patients

People with Psychiatric Disorder and their Families will participate in Psychiatric Decision Making Process

History of Psychiatry (world-wide perspective)

- pre-modern - one of supernaturalities or result of punishment. People with schizophrenia were objects of seclusion
- 19-20c. - one of the medical diseases. Treatments are medication and community treatment

The Japanese Translation of "Schizophrenia"

seishin-bunretsu-byo

sei shin bun retsu byo
mind split disease

Social Background of the Movement of Renaming

- Disclosure of Information and Idea of Informed Consent Became Social Trend
- Our Society must Accept Co-existence with the Disabled
- Normalization

Symbolic Importance of Movement of Renaming

- Japanese Psychiatry Declares Emergence from the Era of Detaining Psychiatric Patients
 - People with Psychiatric Disorder and their Families will Participate in Psychiatric Decision Making Process
-

PROF. SEOK HEE YUN

STRUGGLING DESPERATELY WITH MY DISEASE

My name is Seok Hee Yun, president of the Korean Alliance for the Mentally ill. I will introduce my case, because I think I succeeded in struggling with my mental illness. I am a college professor. I became sick when I was 19 years old. Too much stress made me sick. In Korea there is high school "3rd year's disease". Every high school 3rd year student receives much pressure to enter a good college. Parents want their children to enter a good college. Korean parents believe that getting into a good college means a good job when their child graduates. But this is changing nowadays. So I am one of those who got stressed. That stress led to schizophrenia. Even though I entered college I couldn't study, I couldn't live an ordinary social life. From 20 to 30 years old I was admitted to hospital many time for four months and then discharged, so I became very impaired with much disability. I couldn't do daily work, like cooking, washing dishes, or cleaning the house. It takes a lot of time to become accustomed to this work. Many patients are disappointed because they cannot do simple daily work. It is like a marathon. Getting ahead is one centimetre at a time.

During this time I entered university. Even though I was impaired I wanted to study. I liked chemistry, but finally I got a B.A. in English and then a teacher's certificate by the time I was 28. However, I could not get a job, as I had no confidence that I could work the 9-5 hours.

At 30 my health deteriorated even more because I was not taking medication. I had the delusion that North Korea would take me and make me a spy. I was very afraid to go to North Korea. From childhood we were taught that communists were cruel to people. So I attempted to commit suicide. It was not because of depression. It was because of my delusions. But after taking medication I had no delusions. I became free and peaceful. I realized that these delusions had happened because of a sickness, so from that time on I took medication. I wanted to work and I wanted to live a social life.

At this time I became a volunteer worker at the church. I visited a paralysed man to help him and to befriend him and to talk with him. I did this for 8 years. I taught a primary school course to adults who were not educated, on a volunteer basis. I taught English at the institute.

In Korea there are now many mental health centres. Many consumers can go to these and spend quality time. When I was 35 there was no centre, but I had the benefit of knowing the sister of a nurse, whose house I visited and often played with her children. I also visited my sister's house often. These two houses were my mental health centre.

I began studying at graduate school when I was 39. I studied very hard and got my M.A. degree. I felt a sense of success; I had made tremendous efforts.

By the time I was 42 I had a job at a small foreign trading company where I wrote letters. It was a nine-to-five job that was very difficult for me. Then I began to teach students at a college. I was happy with this opportunity because being a college professor is the most honourable job in Korea. I believed I belonged to a healthy persons' group. I felt that I was not a patient any more. After teaching for three years I married a college professor, but it did not last very long, and after five years I was divorced. My husband had four children. Even though they were adults, I had many things to do for them. I recognized this was beyond my ability. Even though I divorced, I had learned many things. I had become accustomed to good habits, cooking, cleaning the house, washing clothes, etc.

I continued to teach at college, and later began to work with mentally ill persons, telling them how I had been able to overcome my disease and my experiences doing so in order to help them to recover. I teach with passion. I encourage the patients to rehabilitate themselves. I teach English and sing songs with the patients and counsel them. Because I have experienced schizophrenia I understand them.

I am very thankful for the kindness and encouragement of Father Herbast. He was my English teacher when I was at college. He was a Jesuit priest, a man of character. He loved me as a teacher and a student. He always treated me tenderly and with respect. I had a delusion about him that he was looking at me wherever I went. I believed my delusion and told others that he had put a chemical into my cup of juice to increase my libido. Despite this story that I was telling he did not scold me. He continued to help me. I have met with him over 100 times for the last thirty years. He has been like a rock. I know I can lean on him. This kind of unchangeable love cured me and made for healthy living.

I will introduce my mother. My mother was always busy earning money. She supported me mentally and economically. She gave me enough money so that I could go to the institute and improve my English. She never hated me, even though I didn't earn enough money. She always treated me nicely. When I cooked and cleaned my house she always praised me, so that I should respect myself.

About stigma. I go along with friends without any stigma. I admitted to friends that I was mentally ill. My friends are Irish priests and nuns. In Ireland there is little stigma and good welfare for mental patients. I heard in Dublin there is a restaurant that hires several chronically ill patients. In Korea there are not many Western people so I get along with western foreigners as I can speak English well. They welcomed me.

When I was a professor of Bukyung University, I told over 60 students that I had a mental illness. They did not think their teacher was strange, I was brave. When I was a professor of Myunggi Junior College one video producer took my photograph. Another professor asked me, "Why does he take your photograph?" I answered, "Because I got over schizophrenia they are making a documentary." I have always been brave and courageous. God gave me schizophrenia. It is not my fault. Schizophrenia is my destiny. I often shout to myself: "Go away schizophrenia. I am going ahead!"

COPING WITH STIGMA -SAA-SELF HELP SUPPORT GROUP'S EXPERIENCE

GURUDATT KUNDAPURKAR, RAGHUNATH ACHARYA, NEELIMA BAPAT, SULOCHANA HARSHE AND ANIL VARTAK,

Pune, India

Abstract:

A mentally ill person or his relative would generally say, "Stigma is harder than illness itself." The world has come a long way since centuries past when branding, banishing and shackling of the mentally ill was practiced. Despite widespread literacy and the wonderful means of communication of modern day, the stigma shadow follows those afflicted and their families. Stigma, in its different forms, is still practiced consciously and unconsciously. Cultural differences, levels of ignorance and illiteracy and technological development have a large bearing on the suffering of those stigmatized. Schizophrenia Awareness Association (SAA) and its Self-Help Support Group activities in the city of Pune, India, since 1997 have helped in learning more about stigma. Ramifications of stigma and its sting experienced by the mentally afflicted and their caregiver family members are

being shared here. A holistic, 360 degree, approach is needed (1) to find ways of removal of the very causes for stigma and also, owing to the inherent limitation of success of this effort (2) to find ways of coping with residual stigma.

1. INTRODUCTION

Physical illnesses easily arouse sympathy, support and affection from other people. Persons suffering from other physical disabilities, cancer or heart disease receive help from society. But, even though mental illness lies in the same category, it has received apathy, neglect and is generally regarded as a matter of shame and blame, which we call Stigma. It is the experience of some people suffering from mental illness and their caretakers that “Stigma is harder than the illness itself.” According to WHO –disability due to mental illness is the second largest disability among different diseases.

2. EXPERIENCING STIGMA

Many patients commented that other people did not treat them fairly.

- *“Indecent behaviour/gestures/comments scared us.”*
- *“Stopped talking when we used to pass by.”*
- *“Usually avoided us.”*
- *Make remarks like –“how are you now? Have you fully recovered now?”*

“This used to upset us tremendously. We used to feel upset for hours. We used to feel that our value has gone down. All affected persons have strong memories of these incidents, even after a period of 20/30 years. We want to be treated with respect and dignity. The support group has helped us. In school if any one was doing an unacceptable thing teacher used to comment –“Send him to Agra, send him to Yerwada. (Agra and Yerwada are places where public mental hospitals are located.) They used to say “Buy a bus ticket for him for route no. 9.” Bus route no. 9 had a final stop at these hospitals.

Nobody really understood anything but all the children used to laugh. An impression develops in the minds of innocent children that mental illness is very ugly, a matter of shame and bad character. There is nothing in the school and college syllabus giving scientific information about diseases of the brain. Children do not get an opportunity to know the facts about mental illness.

One woman stated that it is this deep feeling of shame, which is perhaps preventing her brother from accepting his disease. Had it been blood pressure or diabetes he would have accepted it easily and accepted medication. “Is this stigma towards mental illness that the persons with mental illness are fighting?” she questioned.

Marriage chances are a great block. There is more pressure of stigma in closed groups, as marriages are usually intergroup. One patient, who was enthusiastic for joining the group, did not do so, as his daughters were at a marriageable age. Some parents do not mind taking their children to social functions but the awkward habits of their children, like going to the toilet frequently, or drinking water repeatedly, made them uncomfortable.

Stigma in the beginning

Several parents admitted that they encountered stigma in the beginning about the illness of their son/daughter. To the inquiries of other people, “What does he do now?” they used to feel uncomfortable. They used to tell a lie “He is doing this and that course.”

This used to bring immense pressure on them. Over a time they learnt to accept it, face such situations and admit facts.

The support group enhanced this process. This reduced stress on them. They felt freer. This changed attitude also became helpful for their child. “Now I welcome my son and introduce him to others when guests come to our house. My own and his socialisation have increased.” This example highlights that most people are sympathetic and have understanding. But we, as parents, are afraid that all other people may not take it in the proper spirit. Parents also need to take the initiative to confront stigma.

Women are more stigmatised than men. Men generally become free from this feeling quite soon but women continue to have it so they avoid socialisation. This itself may be because of their limited exposure to the outside world. Some stigma is also from inside. We, the affected families, create stigma. Usually stigma gets magnified - no doubt, society practices it, but we magnify it, see it in all dimensions. We crumble under own creation. Different family members develop stigma of different intensity depending upon their own personality.

Problems in employment.

One parent informed us that their daughter had the illness and she also had difficulties in doing her work. Father has to visit her office frequently and request her colleagues to take care of her. But, he could not tell them that she had a mental illness, because had he told them this, he feared people might not treat her properly. People may feel – “How can we give her responsible job.” Is that not some sort of ostracism? Could not stress on her and her family have been reduced, had other people taken it rightly? Could not her recovery have been faster; had society taken her illness in good spirit? If the family could accept the illness early, affected persons will benefit more – a patient’s perspective. Parents finding their own coping strategies. One lady told that “If we are weak then people may give you trouble”. One has even written a book on ‘Anand’s journey towards happiness.’

Professionals can play an important role. In the early days and even later, the professional is the only source of information and moral support to the affected person and their family.

3. HOW IS STIGMA GENERATED?

- **Because of misconceptions about mental illness**
 - punishment because of deeds in a previous life.
 - MI is hereditary.
 - MI is a shameful disease. It arises because of bad character/undisciplined/ behaviour/ moral failure.
 - Blame towards family –family is responsible for its occurrence.
 - MI person is always violent.

- Awkward behaviour of affected persons is responsible for feeling of stigma.
- Jokes about madhouse and people with mental illness
- Young persons/children crack jokes where persons with mental illness are shown having illogical/indecent behaviour.
- **Nature of Mental Hospitals in the country.**
 - Up till now hospitalisation facilities were basically provided by government. The conditions of these mental hospitals were certainly not up to the mark.
 - Mental hospitals usually are outside the city and are protected by high walls.
 - Congested nature of these old buildings creates feeling of fear.
- **Role of Media**
 - When media deal with MI, they always show extreme examples.
 - They show usually scenes of Mental Hospitals and patients with violence.
 - They show scenes of shock and show how painful it is.
 - They hardly ever show that having illness does not mean reaching an extreme stage; persons with illness are also good, brilliant, sensitive and kind.
 - Their illness is a physical illness.
 - In literature also persons with MI are grossly misrepresented.
 - These instances, though small, perpetuate wrong beliefs in the minds of people.

4. EFFECTS OF STIGMA

- Isolation of patients and caretakers from society.
- In reality both of them need support from society.
- The person is deprived of benefits of interaction obtained through mixing in society. – man is a social animal.
- Because of isolation, affected person goes deeper and deeper into his problem and his condition deteriorates.
- Family is deprived of channels to reduce stress – for example in social mixing/attending functions/chatting with friends etc.

5. SOLUTIONS -

- Awareness programs for public.
- Short course for understanding and lessening of stigma is necessary. This should include guidance on relaxation/hypnosis/meditation etc.
- Counsellor's help is essential. [Stigma counselling]
- Lobbying and liaison with media.
- Seeking protection of law - severe punishment.
- There is severe punishment against animal cruelty and surprisingly no punishment against cruelty against persons with mental illness
- Improved facilities and maintenance of Mental Hospitals.
- Mental hospitals should be renamed as mental health hospitals.
- Recovered person can play an important role.
- Examples of good work by recovered persons will bring respectability.
- Special efforts are necessary for persons in the age group 14-30 and their families.
- Training resources for parents and social activists are required.
- Parents should form cooperative for providing skills and employment to affected persons. This will give self-respect and self-reliance to persons with MI.
- Parent's initiative/lobbying is required.

6. CONCLUSIONS –

- Involvement of all parties is required – patients, parents, professionals and society.
- Affected persons and parents initiative to confront Stigma is of utmost importance.
- It is not that they have only two choices-
- To disclose everything about their illness.
- To remain silent and anonymous.
- There are several intermediate options, which affected persons, and families can take which are suitable to their capacities and situation.
- Even if they take one step it will be of immense help to them and others.

SPECIAL SESSION - BILL JEFFERIES MEMORIAL PRESENTATION:

Bill Jefferies was the founding president of the WFSAD. He died this year after a battle with Parkinson's disease. Bill fought long and hard for family recognition, against discrimination and for more and better services. He was particularly devoted to promoting more research and to spreading information and education across the world.

SEAN W. FLYNN, MD

Co-Director of Research Riverview Hospital, British Columbia, Canada

TOWARDS RECOVERY – CURRENT IDEAS IN CLINICAL PRACTICE: A CANADIAN PERSPECTIVE

Abstract:

Schizophrenia and related psychoses have plagued mankind perhaps for as long as we have had language. Society's treatment of persons with psychosis has gone through several stages that closely mirror the prevailing political climate. This presentation will review several historic approaches to the treatment of persons with psychosis. Current and future trends in the treatment of psychosis will be discussed.

How do we define schizophrenia? (DSM IV)

- two or more of the following: delusions, hallucinations, disorganized speech, grossly disorganized behaviour, negative symptoms
- social / occupational dysfunction
- duration: 6 months or more
- exclusions
- But the fundamental issue is loss of function due to problems with thinking, feeling, or acting

What causes schizophrenia?

- ? schizophrenia may be the price we pay for being human
- genetics
- obstetrical complications
- prenatal exposure to viral infection
- severe maternal malnutrition

Schizophrenia is a medical condition

- social conditions affect schizophrenia
- institutionalization

Pre-asylum era

- first recorded asylum established in 705 in Baghdad
- hospices in Europe in the 1400's
- Québec in 1633
- America in 1700's

Nazi Doctors in the 1930's

With war approaching, an urgent need was seen for hospital beds. The eugenic movement needed ways to perfect proposed mass euthanasia projects. In 1938 - 9, 140,000 to 200,000 psychiatric patients were put to death.

The 1950's

- Kennedy Commission
- Canadian Mental Health Association report
 - patients are to be treated "as close to their homes as possible"
- chlorpromazine
- deinstitutionalization

Deinstitutionalization vs. dehospitalization

Any increases in community resources fell well short of the economies of deinstitutionalization

"The community may form a background for further treatment. It is not in itself a treatment."

Where next in the treatment of schizophrenia?

- ziprasidone
- aripiprasol
- sonaprisol
- amisulpiride
- depot versions of atypical antipsychotics
- glutamate receptor agonists
- muscarinic receptor agonists
- membrane stabilizers
- gene modulators
- early detection/ intervention
- improved social treatment

Current Canadian research

Research into schizophrenia = more hope for the future

In-vivo visualization of myelin using 32-echo T2 MRI

Alex MacKay, William Honer, Ken Whittall, Irene Vavasour, Siemion Altman, Geoff Smith, Tom Ehmann, Natalia McCarthy
supported by NARSAD and the CIHR

Three brain water reservoirs are distinguishable with 32 echo T₂ MRI

- component of T₂ between 50 and 300 ms: intracellular and extracellular water
- component of T₂ greater than 300 ms: cerebrospinal fluid
- component of T₂ between 0 and 50 ms: myelin water

Myelin signal in chronic schizophrenia

21 males with chronic schizophrenia

- mean age 35.1
- mean length of illness 14.4 years

23 controls matched for gender, age, smoking, and parental education

The myelin signal is significantly lower in all segments in those with schizophrenia as against controls, this difference even more marked in the left genu region. (this is my interpretation of the graphic – need to check with Dr. Flynn!)

Future directions

further assays of the left genu

- application to other psychotic disorders
- correlation of this approach with others:
 - diffusion tensor analysis
 - magnetization transfer
 - spectroscopy
 - MBP
- what treatment implications may myelin abnormalities have?

The problem of non-adherence

- early recognition and treatment
- support and education for consumers and families
- cognitive therapy to reduce symptoms and improve functioning
- intensive rehabilitation aimed at a return to the highest level of functioning possible
- access to adequate housing and jobs
- medications

One year rates of non-adherence

oral antipsychotics	10-76 (50%)
depot antipsychotics	14-36 (35%)
• arthritis	55-71%
• epilepsy	54-82%
• BAD	20-57%
• diabetes	19-80%

Profile of an illness with poor adherence

- chronic
- treatment is suppressive
- treatment not 100% effective
- treatment has significant side effects
- consequences of stopping are delayed

Predictors of non-adherence

- low SES

- unstable lifestyle
- side effects - akathisia
- complex treatment regimen
- younger age
- substance abuse
- male
- negative family attitudes toward medication
- grandiosity, hostility, suspiciousness, disorganization
- poor insight

Optimizing adherence

factors in non-adherence

patient / family factors

- lack of insight
- idiosyncratic concepts of treatment
- fear of stigmatization

physician factors

- poor therapeutic alliance
- lack of education

lack of environmental support

- transportation, money

medication factors

- dysphoric effects
- intolerable side effects
- subtherapeutic / supertherapeutic dose

psychodynamic considerations

psychological meaning of medication

- control
- medication = sickness
- identification with co-patients
- dependence / addiction fears
- fear of the challenges of wellness

psychosis as a maintainer or personality organization

- psychosis may provide self-image
- fear of loss of sick role

transference / countertransference

- prescription = dismissal
- reduced symptoms = reduced physician interest
- physician frustration - "bad" patient

Positive treatment team factors

- the ability to inspire trust
- warm, friendly, competent
- accepting
- aware of patient's needs
- flexible
- optimistic
- negotiating

Second - generation antipsychotics and adherence

improved side effect profile - better acceptance of treatment - less treatment-related dysphoria - improvement in symptoms and cognition - better insight

Cognitive behavioral therapy for schizophrenia

A practical overview of CBT

CBT model of compliance states that virtually everyone is capable of compliance if the treatment is:

- acceptable
- understandable

- manageable

Challenging delusions

- skills to manage voices
- CBT to enhance adherence
- find a patient-centred goal that adherence may help meet
- get patients to predict the factors that might interfere with adherence
- use problem solving to find a way to avoid these obstacles or to cope with them if they occur
- use divided pill boxes
- reminders or help from others

Clinical trials of new medications

What is a clinical trial?

- someone comes up with an idea for a new treatment
- to become a legitimate medication, a long series of research trials, under close government scrutiny, need to be conducted
- these trials can take years and cost millions of \$
- the downside: it takes a long time to get a new treatment
- the upside: we can be pretty sure that, when approved globally, a new medication will be safe and effective

Four phases to clinical trials

- phase I: animal
- phase II: normal human volunteers
- phase III: persons with the illness under study
- phase IV: after a drug is approved, to fine tune our understanding of dose, side effects, etc.

A MULTICENTER, RANDOMIZED, DOUBLE-BLIND, PLACEBO CONTROLLED STUDY OF (A NEW MEDICATION) IN THE TREATMENT OF PERSONS WITH SCHIZOPHRENIA

Clinical trial

purpose: to compare safety and efficacy of (new medication) to (placebo or another medication)

- 6 week with 12 month extension
- outcome measures...
- inclusion criteria: 18-65, Sz (Sz-aff), PANSS > 60, inpatient, informed consent
- exclusion criteria: non-responders (clozapine), in hospital > 14 days, depot, substance abuse, medical condition

Informed consent in research

- patient education
- adequate time for consideration
- free choice
- dynamic, ongoing process
- treatment team / family involved as appropriate
- access to non-investigator physician for capability assessment
- education of staff re: primary responsibility of patient protection
- document patient's understanding of protocol
- respect patient's autonomy
- investigator has ultimate responsibility

Clinical trial

- highest level of care is received
- participants get early access to potentially helpful treatments

Procedure:

- consent - ongoing, family, independent assessment
- blood work
- PANSS / other outcome measures
- nursing assessments
- QOL measures
- adverse events

How to get the most from your mental health team

- in schizophrenia, knowledge is power
- the treatment team should be multidisciplinary
 - psychiatrist

- GP
- psychologist
- nurse
- social worker
- OT /RT
- pharmacist
- community workers
- family

The current concept of mental health care:

- provision of mental health services should be consumer focused
- the family is an essential resource in improving the lives of those with serious mental illness

The five stages of grieving (Kubler-Ross)

- shock and denial
- anger
- bargaining
- depression
- acceptance

What consumers and families should expect from the treatment team:

- they have the right to be treated with dignity and respect
- accurate diagnosis, up to date treatments
- a rundown of the treatment plan
- families and consumers, as much as possible, are seen as partners of the treatment team

Strategies for families:

- nurture a positive relationship with the treatment team
- help the team understand your loved one as a person
- increase your understanding of mental illness
- know your mental health care system
- sharpen your stress management skills

Strategies for consumers and families:

- take time to meet your own advocate
- take care of yourself: diet, exercise, socialize...
- avoid street drugs / alcohol
- take medications as prescribed

Strategies for mental health workers:

- take the time to develop a relationship with the consumer / family
- acquire and provide ongoing education regarding mental illness
- help consumers and families enhance their coping skills
- help family members recognize and meet their own needs
- help the family appreciate the special issues of the person with mental illness
- manage confidentiality issues

Activities families, consumers and mental health workers need to do together:

- lobby for access to new treatments
- continue work aimed at destigmatizing mental illness
- be advocates for improved housing, jobs, medications and resources for the mentally ill
- listen to each other

Thus you can move from helplessness to hopefulness

LET'S JOIN HANDS AND MINDS
WORLD FELLOWSHIP FOR SCHIZOPHRENIA AND ALLIED DISORDERS
BIENNIAL CONFERENCE CHENNAI 2004
LOOKING FORWARD TO MEETING YOU IN
CHENNAI
NOVEMBER 2004