

THE POWER OF THE FAMILY MOVEMENT: CATALYST FOR CHANGE

RADHA SHANKAR MD

Consultant Psychiatrist, Swaram Hospitals, Chennai, India, and WFSAD Board Member

Abstract:

Zenkaren, the world's first organization for families of people with major mental illness, was founded in 1965. In the four decades thereafter, such family organizations have been established in over 50 countries across the world. In developed countries, families and natural caregivers have had to deal with fallacies and entrenched attitudes that have influenced their experiences with the mental health system. However, facts and figures have helped to dispel some of these fallacies, and family organizations are contributing to the slow but definite changes in mental health policy, programs and services, and legislation. The concept of family organizations is an emerging phenomenon in the developing world. Citing India as an example, the presentation discusses the realities that confront families and organizations in the poorer nations, even as they prioritize and help to catalyze the changes that are needed in the mental health sector. The presentation also highlights the universality of the family movement, despite apparent differences and contradictions; it identifies future issues and challenges that require debate and discussion by family organizations, in developed as well as developing countries.

This presentation is in power point only

BRAIN BANK: WORKSHOP 5

PROF. SHINCHI NIWA

Professor, Fukushima Prefectural University, Dept. of Medicine, Neuropsychiatry

Abstract not available.

MICHIKO TAKANO

Abstract not available.

BRAIN BANKS: ONE PATHWAY TO HOPE

JIM CROWE, WFSAD PRESIDENT

Abstract: Brain banking and the research deriving from it is a very long-term undertaking. If a brain-banking project is to succeed over decades it needs to be set up at the outset with a solid ethical foundation. It has to be able to withstand critical scrutiny. Open and free discussion with families and individuals affected by mental illness and with the organizations that represent them is a must.

To have the full understanding and collaboration of the family organisations would be a very important step in ensuring the acceptance and success of any brain-banking project. Brain banking needs to develop with keen awareness of socio-cultural attitudes to death, including the prevailing religious beliefs and practices. It is also necessary to develop a good public profile with the community as a whole, not least because it is necessary to collect brains from unaffected people, as comparison brains.

UNDERSTANDING MENTAL ILLNESS

When a mental illness strikes a family the first question asked is "what did we do" " what happened" " what did we do wrong". Families I have worked with and continue to work with constantly ask themselves such questions. A major mental illness assaults the very being of a family. They will experience grief and loss, utter devastation and a feeling of powerlessness. To try to explain what has happened is rather difficult given that we do not know the cause so a cure at this time is unlikely. Though it must always be mentioned that such illnesses are very treatable. I have always found it very difficult to explain to the individual and their family what the future may have in store for them. Hope must always be forefront to all discussions. Mental illnesses such as schizophrenia are now very treatable with appropriate medications.

For many families being listened to by Mental Health Professionals is the first challenge the families face when they become aware that something is not quite right within their family member. The policy makers and the professionals working in the mental illness area have needed to learn and continue to learn, recognise and respect the important role of families and realise that the intimate knowledge families have can be an invaluable aid to treatment and research. Education is vital to families so that they can understand what the research is about, what it can mean to future understanding about how the illness affects the brain.

BRAIN BANKS

More than 20 years ago, Witelson started a truly unique resource at McMaster University – a brain bank. What sets this bank apart is that her samples are from people who were intellectually and neurologically normal and who agreed in advance of their deaths to undergo interviews and neurological tests that would profile their cognitive abilities for eventual comparison with their brain's anatomy. This was the beginning of what we now call brain banks.

During the past decade, the use of post-mortem brain tissue for neuroscience research has led to some important advances in our understanding of the underlying neurobiology of mental disorders. Many exciting discoveries have begun to emerge, however, it must also be said that there continues to be a severe shortage of human brain specimens from individuals diagnosed with schizophrenia and bipolar disorder available for this kind of research.

The lack of donated brain specimens from individuals with mental illness acts as a limiting factor in research, and it has had the effect of impeding the overall progress in post-mortem neuroscience research. In order to propel state-of-the-art programs of post-mortem research into the next millennium, a greater awareness about the essential need for brain donation must not only be understood, but also embraced by families affected with mental illness. Making a commitment to brain donation provides a unique and important opportunity to make a significant difference to both current and future brain research.

At this point I wish to mention the success rate for treating mental illness, as we know it at present:

Heart disease has a 45 to 50 percent treatment success rate.
The success rate for treating Schizophrenia is 60 percent
The success rate for treating BI-polar is 80 to 90 percent
The success rate for treating panic disorder is 70 to 90 percent
The success rate for obsessive-compulsive disorder is 75 percent
The success rate for treating depression it is 70 to 80 percent
(With thanks to NAMI for those statistics)

It is so vitally important to show families that hope is always there and that over the years important progress has been made in the treatment of mental illness. Through brain donation, families affected by mental illness have a special role in helping the neuroscience research community continue to make progress in its collective effort to lift the veil of mystery about the complex nature of these debilitating disorders. Ultimately, affected individuals and families are the only ones who can give this very special gift so that others in the future may be free from mental illness. Always keep foremost in your thoughts that - From knowledge will come a cure! Education is vital to families so that they can understand what the research is about, what it can mean to future understanding about how the illness affects the brain.

COLLABORATION

Positive collaboration is going to be vital for both the families and researchers. In whatever country that one wishes to establish a brain bank the full collaboration and understanding of a national family organisation is crucial. This is crucial for the acceptance and overall success of the project. The whole family must understand fully the implications of what it means to be part of brain research and the donation of a loved one's brain at the time of death.

I would hope that the researchers would spend some considerable time both with the donor and the family. The family needs to understand the hope that research can bring. But in saying that it should also be mentioned that it would be a long term investigation. That such research takes time and may not in their lifetime produce results. I have spent some time with families in New Zealand talking about such research. It was not easy as we were talking about the future death of a loved one. It also raised one of the most common questions " what happens if we are not here" who will look my loved one. It was the dignity of the person that they were talking about. Overall what it reflected was the absolute need to involve the WHOLE family.

On my driver's license it says donor. In New Zealand we now have new licenses, which reflect this. I had it put onto mine and forgotten about it. When my license arrived by mail my wife noticed that I had put in donor. I can safely say that I got some reaction, as I had not mentioned it. I had not thought it important. It was very important for my wife to know that it was my intention to be a donor. In fact in my family we have had the experience of donating a kidney recently. This was not an easy time. To me it reflects what we are discussing here. My family became involved, as did my wife's whole family. I can assure you a lot of discussion took place before a final decision was made. The transplant went ahead very successfully for both sides.

Let me assure you that good positive communication is absolutely crucial at all times. Our experiences with the hospital system immediately before and after the transplant were not good. My wife felt she was an object, useful to the health system and saved that system a lot of monetary expense. Her health needs for a good fast recovery were overlooked.

SPIRITUALITY

More than any other donated organ the spirituality of the brain comes into the picture. To so many people the brain reflects their whole being, their soul, their present existence and a pathway towards wholeness. The religious beliefs in different countries will also play a major part in this area. In Japan you will have Shinto, Buddhism and Christianity. Each religion will play a vital role for the person who makes a donation of his or her brain. One's spirituality plays a vital part it is the essence of one's being. I can see that researchers are going to have to spend time with the families and the community at large educating them as to how they can by donating their brain give those in need hope for the future. The dignity of the person and his/her family must be upheld at all times.

Japan is a country steeped in traditions. The Japanese tradition and values originated in ancient Chinese Confucianism. Confucian ethics emphasized the individual's connectedness with the natural world and other people. A basic Japanese value, compatible with Confucianism, emphasized harmonious human relationships. Japanese culture today still encourages harmony, mild, and good interactions between people. The Japanese world view, also based on Confucianism, emphasis's interdependence. Taoism and the belief of the Ying and the Yang also play a role in the Japanese world view.

Overall cultural beliefs and religious beliefs are going to play a vital part in the success of the brain bank project. Some of you present represent Shinto, Confucianism, Buddhist traditions. One's personal spirituality also plays a significant part. We need therefore to find ways of moving ahead. This is where we need to be able to discuss the long standing traditions and beliefs with significant religious leaders.

We will need to attempt to find a path towards acceptance of being able to make a donation and still be able to live within one's own traditional belief. This may not be a very easy task. But, I do believe that this must be achieved if we are to make any advance in this area. We need to begin those discussions now rather than later.

CONCLUSION

In conclusion I wish to state that the partnership between the families, community and the researchers is extremely important. You need each other to achieve your goals. Together you will need to be prepared to speak to local communities, service clubs and national bodies

To the researcher's I wish to say that my firm belief is that the families play a very powerful role in establishing a brain bank. They are your most powerful allies. It is the families who will make this happen. When I talk of the family I naturally include everyone involved. They are the core of this project. As the families are powerful in this area, Zenkaren is even more powerful as a national family organisation. Zenkaren has a national network of some 170,000 members. I am sure if you were able to set up a working protocol with Zenkaren it would be of benefit to all. You may have already started to do this.

I mention this as another way forward. Without the full support of the family the project may falter or move so slowly as to be non-existent. What I am promoting here is Families as Partners in the setting up of an Asian Brain Bank. I will certainly do whatever I can to help. I am mindful of the NAMI slogan **"Nothing about us without us"**

To Professor Niwa and his colleagues may I say that I have great respect for the leadership and vision you have shown and the tenacity to make it happen. Your work will no doubt be of considerable importance to all who are affected by a major mental illness. I wish you every success as you move forward to the future.

TOKUO UEMORI, *Family Group Member at Kanagawa*

Abstract: Closer cooperation between scientists and consumers/family members will be a key factor to further investigations into the complicated functions of our brain system. There is a great need to study human brain tissue and this is why a brain bank's function is to collect, and store tissue ready for distribution to leading neuroscience researchers. By building a database of willing donors, researchers are developing a resource of well-characterized tissue that offers unique opportunities for medical research. My father and two brothers were severe cases of schizophrenia. They either killed themselves or died in a mental hospital after 38 years' confinement. My own son is another case. Something genetically wrong is at work in my family tree. That is why I decided to be a brain donor.

MARILYN MITCHELL

Patron, NISAD Gift of Hope Brain Tissue Donor Program, Consumer Educator and Advocate

Brain Banking from a Consumer Perspective: The Neuroscience Institute of Schizophrenia and Allied Disorders (NISAD) Gift of Hope Brain Tissue Donor Program (Sydney, Australia).

Abstract: I will begin by stating what the NISAD Gift of Hope program is and how it functions. I will give a thumbnail sketch of myself and how my family has been greatly affected by mental illness. I also outline my reasons for becoming a donor so that future generations of my family and others can benefit from research using my own and other's brain tissue after death. I will also discuss some of the possible benefits that could ensue from the study of post-mortem brain tissue of people such as me who decide to leave their brains to neuroscience research, along with information obtained when alive. I will return to my own experiences to discuss how I believe we can learn from the past. My talk will conclude by outlining the achievements of NISAD's Gift of Hope brain tissue donor program thus far, including information about donors, what is currently being investigated and what are the hopes for future research. New findings, such as those leading to improved medications, can be important but need to be used in conjunction with other aspects of therapeutic intervention. For example, there may need to be lifestyle adjustments in order to minimize the possibility of relapse. It may take time, effort and money; however, the outcomes can be significant not only in monetary terms, but also (most importantly) in terms of human suffering, especially for the patient but also for their families and the community.

EMPOWERMENT OF THE FAMILY: WORKSHOP 6

LILIAN KANAIYA

Chairman Kenya Schizophrenia Foundation, and WFSAD Board Member

Abstract: The Kenya Schizophrenia Foundation has been in operation for just over five years. During this time there have been many successes and some disappointments. My paper will describe what we have achieved and the challenges ahead.

The Empowerment of Family

Distinguished guests, ladies and gentlemen, I feel greatly honoured to have this opportunity to address you today. I am happy to give you a brief background of the work that my organization has started in its efforts to "empower the families" of the mentally ill. Schizophrenia Foundation of Kenya (SFK) is a family support group registered in 1997 as a charitable trust. SFK is in the process of establishing branches in various parts of Kenya. We now have branches in Nairobi and Nyahururu, a rural area.

The founders consist of relatives, friends, and concerned social and medical professionals who work together to establish support systems for patients and their families. They share experiences, conduct advocacy initiatives and work with available resources.

The main objectives of SFK are:

- Advocating for the interests of the mentally ill in their efforts to become self-reliant
- To be an educational resource for families and the community at large
- create support services for families, care-givers and consumers
- To help fight stigma and discrimination

In Kenya, like many other countries, mental illness continues to be stigmatised, ignored and rejected. Mental illness is misunderstood and is mainly explained through negative cultural beliefs and so continues to be shrouded in mystery. This is attributed to the public lack of awareness of mental illness and hence the obvious stigma associated with it. Mental illness has not been given the prominence it deserves though it is known to be one of the leading health problems in Kenya. Government and health officials recognise its existence, but allocate inadequate resources.

In the face of wide-spread stigma and lack of attention to the plight of the mentally ill, my organization is working towards the placement of mental health issues on the national agenda.

We come together once a month to share experiences and to learn more about coping and management of these disorders. Specialists in various areas are invited to work with us to help with the understanding of medication management. In addition we provide information to members on these topics. Everything that SFK does helps families to counter stigma and accept that mental illness is an illness like any other.

In addition to the support group we have set up a working committee that gets together once a month to work on current issues. This year our plans have included finding working partners to help us set up the badly needed family education programs. We have appealed to various institutions to forge a working partnership with us in any capacity, so as to champion the awareness and education campaign.

Institutions approached so far are the World Psychiatric Association (WPA), the Kenya Ministry of Health, mass media houses, social institutions, pharmaceutical companies, various church organizations and educational institutions.

A separate committee comprising members of SFK and Chiromo Lane Medical Centre was set up to train trainers on the anti-stigma campaign program, following the global training guide by WPA. As a result, an anti-stigma campaign was launched in March, 2001. The Director of Mental Health at the Ministry of Health presided over the event. The team's main mission is to create awareness and sensitize the public on: The Magnitude, the Impact, and the Management of Mental Illness. SFK believes that the campaign is the only key to understanding the major mental health issues, which need urgent attention. We find that awareness creation and education are the major tools in fighting stigma and discrimination.. However, we are still handicapped by lack of financial and other resources for effective interventions.

The SFK First National Family Education two-day workshop, funded by the World Health **Organization**, was conducted last March.

Challenges

- We need to overcome the low level of family enrolment in SFK owing to stigma, which discourages openness about the illness.
- We need to instil compassionate treatment from our health care workers at all levels
- We need to find a means to be able to provide people with up-to-date, but expensive, medications, which are out of reach owing to the severe poverty in the country
- We need to raise our profile so that health professionals readily approach SFK to join and support us.

Our needs are many and we cannot achieve them all, but we hope to approach them on a priority basis and gradually overcome the barriers. At the present the following issues are most pressing.

Urgent needs for the organization

- To establish a secretariat
- To recruit more voluntary workers
- To recruit active and committed members on an on-going basis
- To hire voluntary counsellors
- To have a centrally located meeting place
- To translate WFSAD family education materials into Kiswahili (the local language)
- To begin an SFK newsletter

Urgent needs to support people with mental illness

- To establish a rehabilitation centre and residence

- To have the capacity to conduct home visits for face-to-face intervention

We have many challenges ahead of us. We cannot solve them all at once, but with perseverance we are confident that our goal of compassionate mental health care will eventually be achieved.

DR. TATIANA SOLOKHINA
"New Choices", Moscow

Russia

Charitable organizations for both consumers, families and professionals are common in the west. In Russia such activities began in the 90s with the study of the complex problems existing in families living with schizophrenia and the formation of a psycho-educational program. In June 2002 we registered the "Regional Charity Public Center of Social-psychological and Informational Support" : "Family and Mental Health". The paper will describe our activities to promote well-being through various therapies and up-to-date treatments.

REV. WOONG-DAL SONG
Korean Family Association

Korea

This presentation will describe the work of the Korean Family Association in helping families and their relatives who are unwell to understand, manage and cope with mental illness.

YOSHIE KITAMURA
Vice President, Kyoto Prefectural Family Association

Japan

Sharing sadness and agony in common would often be an initial stage of participating in a family self-support group's meetings. Speaking to others about what happened to your family is surely difficult at first. But cope with it for your loved one. In Kyoto we established a committee on a larger scale in 1992. It consisted of six separate family groups now beginning to work together. We lifted up our voice to make administrative services more efficient. It is a shame that Health, Labor and Welfare Ministry in Japan has been so slow in giving approval to allow some of effective atypical antipsychotics produced abroad to be used in Japan. On our part there is one thing that we must learn and practice: we have to facilitate communication with the doctors.

HUMAN RIGHTS: WORKSHOP 7

PROF. AMITA DHANDA
National Academy of Legal Studies, Hyderabad, India

Legislative Agendas and Human Rights of Persons with Mental Illness

Legislation regulates the care and treatment of persons with mental illness. The impact of mental illness on the civil capacities of afflicted persons is also a subject of legislative control. Over the years, whilst the care and treatment legislation has invited intense human rights scrutiny; similar attention has not been bestowed on the civil capacity laws. It is contended that these civil capacity laws reinforce negative perceptions of mental illness and impede the community living of persons with mental illness. This happens because the law uses exclusion as the primary method of dealing with mental illness. Using the Indian legal regime as a case study the paper examines the negative impact of civil capacity laws and sets up an argument for their rigorous interrogation.

IRA BURNIM
Legal Director, Bazelon Center for Mental Health Law

Abstract not available.

FAMILY EDUCATION, REHABILITATION & EMPLOYMENT: WORKSHOP 8

CHRISTOPHER S. AMENSON, PH.D.
Assistant Professor, University of California at Los Angeles
Faculty Chairman, Pacific Clinics Institute

YOSHIHIRO MATSUSHIMA, L.C.S.W.
Adjunct Professor, California State University at Long Beach
Director, Coastal Asian Pacific Mental Health Center (retired)

Tailoring Education To Fit Diverse Families

This first part of the workshop recognizes the universal need for family education and focuses on the variety of methods required to tailor education for diverse families. It is based on the presenters' experience supervising professionals who have educated 40,000 families in 8 languages. The workshop presents methods for 1) engaging diverse families, including families reluctant to use psychiatric services; 2) allying with families to address their goals; 3) discovering with the family the methods that work for them; and 4) evaluating interventions based on their effectiveness in meeting family goals. The workshop describes the types of families that accept and benefit from varied educational interventions, including classes and individual education; verbal, print, and video information; lecture, discussion, and exercise formats; content, style, and pacing of information; and trainer and setting characteristics. Slides from the English, Spanish, and Japanese versions of Schizophrenia: A Family Education Curriculum will be used to demonstrate these principles.

Participants will receive Guidelines for Engaging Families from Diverse Cultures Who Have a Member with Mental Illness, which presents 32 interventions for engaging families from diverse cultures, including families who are reluctant to use psychiatric services or have few economic and psychosocial resources.

DR. BEA DIXON

Executive Director, Kitsap Mental Health Center, Washington State (with the assistance of staff from the Center).

From hospitalization to employment in 90 days?

We are a semi-rural community mental health center where resources are limited and stigma runs deep. Two years ago we visited "The Village", an award-winning rehabilitation agency in an urban area of California, and confirmed that other programs feel the way we do: in spite of their illnesses people suffering a brain disorder can join the work force, re-engage into the community and share their strengths with others. We decided to take our services a step further and started measuring our successes against that of the Village. This paper describes our achievements. Prepared with the assistance of Kathe Koko, Francie Scholl, Patricia Lovett, Joyce Troyer-Wilson and Endre Voros.

FAMILY PSYCHOEDUCATION: WORKSHOP 9A

DALE JOHNSON, PHD.

Professor of Psychology, & WFSAD President Elect

Better Outcomes for Family Psychoeducation

Families of people with serious mental illness need information, but they also need special skills in order to cope and to assist in the treatment and rehabilitation process. Family education is useful, but family psychoeducation which is longer and includes the patient provides better outcomes. How families can participate in this intervention is discussed. Emphasis is placed on how families, patients and professionals can work together productively.

SUSIE KIM, RN, DNSc, FAAN

Ewha Womans University, College of Nursing Science, & WFSAD Board Member

Psychoeducation for family members: Interpersonal Caring Techniques

This psychoeducation for family members presents the interpersonal caring techniques that can be a guide for better relationship between the patient and family members. The effects of the techniques were clinically proven through quasi-experimental research studies. These techniques include noticing, participating, sharing, active listening, complimenting, companionship, comforting, hoping, forgiving, and accepting. The meaning of each technique and methods will be explained with specific and practical examples.

ISHITA SANYAL

Turning Point, Kolkata, India

Sibling involvement in Psychoeducation

The paper discusses the benefits to patients, in reduced relapse rate and reduced symptoms, achieved when siblings are included in family psychoeducation. Siblings, when adapting from secondary to key roles, are able to provide effective levels of support, sharing, a positive attitude and care. Psychoeducation helps them think objectively and rationally and thus help patients more effectively than parents. In addition patients improve their functioning and there is greater well-being in the family.

CURRENT MEDICATIONS: WORKSHOP 9B

SEAN W. FLYNN, MD

Co-Director of Research, Riverview Hospital, Port Coquitlam, B.C. Canada

Current Medications

Medications form the backbone of any treatment approach for schizophrenia. What medications might be used and why? What happens if someone does not respond to treatment? What about alternative therapies? What, other than medications, is needed? A practical, hands on approach to managing schizophrenia will be discussed.