The Winston Churchill Memorial Trust of Australia

Report by Kanthi Perera

2005 Churchill Fellow

An Investigation of innovative programs that address loss and grief in the context of mental illness in order to minimize the distress and trauma experienced by both the person with the diagnosis and his/her family.

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Introduction

The Fellowship enabled me to travel to Canada and the United States of America to study innovative programs that address losses and grief in the context of mental illness in order to minimize the distress and trauma experienced by both the person with the diagnosis and his/her family. This report provides a summary of knowledge and experience gained in the area of ambiguous loss.

I am grateful to The Winston Churchill Memorial Trust for the opportunity to undertake this study tour. Sir Winston Churchill by his brilliant orations and strong leadership during World War II is among the many people with a mental illness who have enriched our lives. “Black Dog” was a term coined by him to refer to his own depression. As such, I feel privileged to have been a recipient of a Fellowship on this, the 40th Anniversary of the Churchill Trust. This report is dedicated to the many courageous people with mental illness and their families who have enriched my life.

I enjoyed the hospitality of my North American colleagues and thank them for welcoming me to their organizations and generously sharing knowledge, ideas and resources. I look forward to a warm association with them in the future.

I am very grateful to Professor Emeritus Pauline Boss of the Department of Family Social Science, University of Minnesota, the principal theorist of the concept of “ambiguous loss”, and an internationally recognized expert on loss and trauma, who has been a mentor to me in this project. As her guest, I was welcomed by many organizations in New York to attend workshops, seminars and site visits. I thank Dr Ann Hodge and my employers North Metropolitan Health Service for granting me study leave to undertake the tour. I look forward to their continued support in implementation and dissemination of my knowledge. Thanks also to my son, Gehann, for his continued love, support and encouragement in pursuing my passion for knowledge in the area of loss and grief associated with mental illness.
Executive Summary
Kanthi Perera
Senior Social Worker
North Metropolitan Health Service, Subiaco Community Mental Health
2 Nicholson Road, Subiaco, WA 6019
(08) 9489 7200. Email: kanthi.perera@health.wa.gov.au

The Fellowship travel was undertaken between 12th October and 9th December 2005. The aim of the fellowship was to investigate innovative programs that address loss and grief in the context of mental illness in order to minimize the distress and trauma experienced by both the person with the diagnosis and his/her family. Particular emphasis was given to programs that promoted family resilience and connectedness by addressing complicating factors that hamper the healing process in mental illness e.g. differential grief, lack of rituals, stigma and effects of negative symptoms of the illness.

Highlights:
- Participating with Virginia Lafond in the ritual of the 7th Ceremonial Iris Planting of The Schizophrenia Society of Ontario's Ottawa Chapter.
- Learning from Associate Professor Kathleen Gilbert, Indiana University.
- Learning through participation with Connie Clarke, Chaplain in inpatient groups of grief and loss at the Wyoming State Hospital, Evanston.
- Learning from Professor Emeritus Mona Wasow, University of Wisconsin the skills of fostering hope when working with people with mental illness and their families.
- Learning from Professor Emeritus Pauline Boss at the International Trauma Studies Program, the concept of “ambiguous loss” and the skills of promoting family resilience and connectedness.
- Experiencing the many benefits of alternative therapies provided by the World Trade Center Healing Services.

Recommendations:
- Raise awareness of the concept of “ambiguous loss” with consumers, caregivers and service providers of mental health services in Australia.
- In partnership with consumer and caregiver mental health organizations of WA, develop a family focused program on ambiguous loss, which will complement the new Carers’ Recognition Act.
- Develop formal training opportunities for those who wish to work with people experiencing ambiguous loss both in mental health and other services.

Implementation and Dissemination
- The knowledge and experience gained will be used to develop a family focused program to address ambiguous loss associated with mental illness in partnership with consumer and caregiver organizations.
- Knowledge will be disseminated through workshops, presentations and articles submitted to newsletters of consumer, caregiver and professional organizations.
Fellowship Program

17th – 21st October 2005, Royal Ottawa Hospital, Canada

- Interview for Ed Hand, Journalist of Ottawa Citizen’s City Desk, Cable Television, on grief associated with mental illness
- Presentation of research findings of *Grief of Parents of People with Mental Illness* to The Schizophrenia Society of Ontario’s Ottawa Chapter

25th October – 2nd November 2005, Indiana University, Bloomington, USA

- Meeting and learning from Associate Professor Kathy Gilbert, The Department of Applied Health Science.
- Presentation of information on *Family Work in Mental Health* to the Indiana University Students’ Council of Family Relations.

7th November – 12th November, Wyoming State Hospital, Evanston, Wyoming, USA

- Participating in group programs with Chaplain, Connie Clark.
- Enjoying daily lunch in the patient-run cafeteria known as “Give Back” program.
- Presentation of information on *Family Work in Mental Health* to Clinical Staff of the State Wyoming Hospital.
- Meetings with Heads of Social Work, Psychology and vocational therapy services to discuss programs.

13th – 21st November 2005, School of Social Work, University of Wisconsin, Madison, USA

- Sharing knowledge with Professor Emeritus Mona Wasow, author of book *The Skipping Stone, Ripple Effects of Mental Illness on the Family*.
- Meetings with David LaCount, Lecturer and 11 Master of Social Work students on field placements in mental health services in Dane County, Madison who introduced me to the concept of *Procovery*.
- Participation in meeting of Professor Wasow and students of University of Wisconsin to set up a campus branch of the National Alliance of the Mentally Ill (NAMI).
- Participating in a NAMI group for partners and spouses of people with mental illness known as “Other Half” group.
- Meeting with faculty staff Barbara Hughes, Betty Kramer and Mary Ann Test and learning about losses throughout the lifespan.
- Meeting with members of *Yahara House*, modeled after corporate worksite wellness programs.
- Meeting staff and members of *Off the Square Club*, a drop-in center for adults with long-term mental illness.
- Annual Recognition Dinner of *Porcllight Inc (Solutions to Homelessness)* and their Silent Auction.
• Meeting with Ms Nancy Abraham, Founding Member of National Alliance for the Mentally Ill, Dane County.

22nd November – 9th December 2005, New York City, USA

• Learning and sharing knowledge with Professor Pauline Boss author of books *Ambiguous Loss* and *Loss, Trauma, and Resilience: Therapeutic Work with Ambiguous Loss*.
• Meeting and learning from Acting Associate Dean Roberta Graziano at Hunter College School of Social Work, an expert on clinical work with survivors of trauma.
• Meeting and learning from Ms Lorraine Beaulieu, Project Union Outreach, a community-based service for families of union workers missing after the 9/11 attack in New York City.
• Meeting and learning from Francine Furman, Director Employer Assistance Program, World Trade Center Healing Services, Saint Vincent Catholic Medical Centers and experiencing the services offered by their Integrative Stress Management Program.
• Attending workshops at the International Trauma Studies Program and the Alzheimer's Association of New York facilitated by Professor Pauline Boss.
• Attending the New York Red Apple Chapter Association for the Advancement of Social Work with Groups’ presentation of *Healing Trauma and Loss Through a Community Based Multi Family Group with Latino Immigrants*.
• Meeting and learning from Trace Rosel, Clinical Coordinator, World Trade Center Healing Services in the downtown Business District of Manhattan near Ground Zero.
• Meeting and learning from Martha Edwards, President, Ackerman Institute for the Family
• Meeting and learning from Susan Sabor, Director, World Trade Center Healing Services.
• Meeting and collaborating with Judith Goldsmith Leventhal and Leo J. Shea III at Rusk Institute of Rehabilitation Medicine.
• Attending the Christmas celebration of the Greenwich Village Chamber of Commerce.

12th December 2005 return to Perth, West Australia.
Loss and trauma associated with mental illness

*Human Rights & Mental Illness*, Report of the National Inquiry into the Human Rights of People with Mental Illness (Australian Government Publishing Service, 1993) was made possible by the many written and oral submissions received from people affected by mental illness and their caregivers. Following are some of the excerpts from submissions about the emotional impact of mental illness upon the family:

“It is an ongoing trauma, you lose your son during the illness but…. You can’t sort of grieve and [then] think you’ve got your life back again. Every time he goes into hospital we grieve all over again”.

*Volume 1, page 469*

Try to imagine our shock when, at the age of 18, our son develops symptoms of a mental illness. Try to imagine the grief that struck our family when this wonderful, active person with so much ability and potential for a good life was “crippled” mentally”.

*Volume 1, page 469*

A teenage boy whose young sister has schizophrenia described the following situation:

*My little sister became steadily worse which caused divisions within our family. Dad could not see the things, which Mum noticed my sister was saying… By New Year’s Eve I thought our whole family was going crazy. Tiny problems would turn into loud arguments everyone was on edge. Anytime there was peace [my sister] was sure to end it.*

*Volume 1, page 472*

The first quotation from a parent gives an example of an ongoing trauma that lacks closure because of the episodic nature of mental illnesses. The second gives an example how a person affected may be physically present but psychologically absent to others around them because thought processes, moods and emotions are affected by mental illness. Losses that lack clarity are ambiguous and can lead to sharply different assessments by family members of exactly who or what has been lost and can cause division within the healthiest of families. The third quotation is an example of divisions that are caused by the ambiguity of mental illness. All of the above are normal reactions to ambiguous loss.

Existing grief therapies, rituals and community supports only address clear-cut loss such as death. The trauma and losses of mental illness is not clear-cut and has no closure. Therefore traditional grief therapies are ineffective in such situations.

**Loss, Trauma, and Resilience: Therapeutic Work with Ambiguous Loss**

Losses that are incomplete, uncertain and lack resolution are termed “ambiguous losses”. Professor Pauline Boss offers a new “lens” for helping
individuals, families and communities facing losses that lack resolution. She does so by setting the stage for families to share perceptions and interpretations of what has been lost and what remains the same thus assisting them find meaning and discover hope in the face of uncertainty. Interventions that stimulate both the emotions and the mind are encouraged and are of value to those whose thought processes, emotions and moods are affected. By co-constructing personal and family roles, rules and rituals, families are encouraged to function despite the presence of an ambiguous loss.

Although Professor Boss’ research and clinical work goes back to the early 1970’s, more recently her model has gained popularity in North America as the more traditional theories and interventions for grief, loss and stress following trauma have been ineffective for assisting clients in catastrophic or unexpected types of ambiguous loss situations. Examples are post 9/11 in New York and more recently in New Orleans following Hurricane Katrina where a loved one may be physically missing with no bodies found to confirm the death. Other situations of ambiguity are where loved ones are lost ambiguously from chronic mental and physical illnesses that rob the mind or body.

The model is a preventative model in that it prevents family breakdown and substance abuse. It is a model based on strengths and thus differs from the traditional models adopted in mental health services of focusing on signs and symptoms. In North America the model is used in mental health services for older adults experiencing Alzheimer’s and dementia but has not been used among the younger population with other mental health disorders. This model is also successfully applied in other situations of ambiguous loss such as trauma caused by acts of terrorism, natural disasters, war or people who have gone missing.

An important lesson that I learnt is that a person’s response to ambiguous loss often is similar to that of post-traumatic stress e.g. anxiety, panic attacks, depression. However in ambiguous loss, it is the lack of clarity that causes these responses. Therapeutic work in ambiguous loss need to be different to that of responses to Post Traumatic Stress Disorder as the “triggering event” of the stress is still present in the person’s life.

Discussions with Associate Professor Kathleen Gilbert and students of the Department of Applied Health Science at Indiana University enriched my understanding of emotional, physiological, intellectual, spiritual, sociological and behavioral reactions of loss and interventions that are effective in alleviating the distress of these reactions.
From our discussions I also gained a deeper understanding of differential grief where family members deal with different issues at varied points in their grief process and sometimes with contrasting styles that may cause division in relationships. Contrasting styles of grieving in families is more common than matched grieving but it can lead to division in relationships, especially if the expectation is that members, having had the same loss, will grieve in the same way. To promote family connectedness, it is important to actively involve as many members of a family in the construction of meaning of the loss. The community based multi family groups with Latino immigrants following 9/11, was structured to enable personal and confidential issues to be discussed with facilitators individually or within the adolescents or parents groups and coming to an agreement of which issues are to be discussed and what are not to be discussed with each other. Caregivers in mental health services have had concerns that laws governing confidentiality frequently keep both families and clinicians from receiving the information they need to provide the best care for people. From the knowledge gained in participating in the programs I visited, I believe a similar framework could be used in the family focused ambiguous loss programs. Such a framework will complement the new Carers Recognition Act of West Australia, which has been proclaimed in Parliament but not yet implemented by service providers.

Including the ‘psychological’ family of those affected is an important aspect to remember in therapeutic work. According to Professor Boss, a useful question to ask a person is, “whom would you like to invite to an important celebration of yours, such as graduation or birthday celebration?” People usually include their “psychological” family or those they find supportive. Including a person’s “psychological” family in discussions helps those present “brainstorm” ideas to find more options to overcome their distress. When people understand that they have options, they feel less constrained.

Supportive communication facilitates the discussion of thoughts and emotions and assists each member share their beliefs about the loss and it’s meaning for them whilst at the same time allowing and accepting differences. There will be individual meaning of the mental illness and losses experienced by each member but there also will be collective meaning of the illness and losses experienced as a family.

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**Involving as many members of a family, including the ‘psychological’ family assists in constructing meaning of the loss and brainstorming realistic options for overcoming distress.**

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Co-construction of family roles and rituals will assist each member to contribute toward maintaining family cohesion and healing. This will also avoid one member of the family taking more responsibility and burning out as a consequence. I was particularly fortunate to be in New York during the weekend of Thanksgiving to witness families come together to continue an important ritual of sharing a family meal together. I participated in a family gathering where they discussed where each person was on that fateful day of 9/11 and the different meanings they had given to the incident, individually
and also collectively. Those who lived in New York believed that their assistance in caring for the rescue workers contributed to their own healing of trauma.

My knowledge of gender differences in reaction to loss and coping styles was also further enriched by my discussions with Associate Professor Gilbert. Research and clinical observation has shown that men experience disenfranchisement of their grief because of gender expectations regarding appropriate male behavior after loss. Research finding also suggest that men cope by behavioral rather than cognitive methods.

I recommend that therapeutic work of a family focused ambiguous loss program take into account gender differences in coping with loss associated in mental illness.

As a result of our meeting and collaboration, Associate Professor Gilbert and I will be contributing an article on Ambiguous Loss Associated with Mental Illness to a special issue of an Interdisciplinary Journal of Applied Family Studies, Family Relations for publication in Volume 56 (2) of, April 2007.

In order to be aware of the losses affecting communities we need to be aware of the losses affecting individuals, groups and vice versa. Whilst in my Churchill travels I witnessed the importance of working at these different levels to address trauma, promote healing and reduce stigma of mental illness. The Annual Recognition Dinner of Porchlight Inc in Madison was an example where I heard stories of people with mental illness who had overcome homelessness to find stability and success in their lives. Service providers of mental health services were involved with the local business community through Porchlight Inc to find solutions for homelessness. Funds were raised through silent auctions. Similarly, staff of the World Trade Center Healing Service has joined the Greenwich Village Chamber of Commerce. Through their networking they are breaking down barriers in order to heal the traumas of 9/11.

I believe that service providers in mental health services need to be encouraged to work not only in assisting individuals but also working within groups and in community development.

Whilst on my travels, I witnessed and experienced cost-effective ways of healing loss and trauma offered by The World Trade Center Healing Service at St Vincent Medical Center through modalities such as ear acupuncture, Reiki, hypnosis, Tai Chi, energy work, Feldenkrais, therapeutic art and music. These services arose from the need to marshal quick assistance for those affected, with little time for planning because of the sudden occurrence of 9/11. Initially, therapists volunteered their services, however, because of the success of the program, the Center has received funding through American Red Cross to continue this program until 2008. In Greenwich Village the healing services are offered on a Tuesday evening each week. All therapies
are offered at the same time in different rooms, giving attendees a ‘buffet’ from which to choose. They are encouraged to try each modality and see if it is of benefit to them. Thus they are given choices and control of the services. In the Downtown Business district, ear acupuncture and energy work is offered at lunchtime on a Tuesday of each week.

These services are now offered not only for those directly affected but also for those who assisted in the rescue and recovery work at Ground Zero who were so busy at that time in taking care of those in need, they did not take the time or opportunity to care for themselves. Healing is promoted when people are given choices and control. Because these modalities are non-verbal, they are less threatening and will be of special benefit for those who have difficulty with thought processes. As they are offered to groups of people, it has promoted a sense of community. They are cost effective because they cost less than the traditional “talking therapies”.

I recommend that non-verbal modalities of treatment are included in the family focused ambiguous loss program and offered to consumers and their caregivers as a group to heal their losses and promote a sense of family connectedness. These modalities have the potential to be of special benefit for those whose thought processes are affected and also alleviate distressing physiological and emotional reactions.

Ceramic Therapeutic Art near St Vincent’ Hospital
Greenwich Village (World Trade Centre Healing Service)

Hope is an important concept for healing trauma
Two concepts of learning that were recurrent in my investigation of loss and grief programs was the “search for meaning” inherent in all forms of suffering and the importance of “hope” in finding meaning. People with mental illness and their relatives often question, “why me?” or “why this?” whilst they attempt to discover, determine or create a sense of meaning to the illness.

The work of Viktor Frankl in his book *Man’s Search for Meaning* is often quoted by therapists where he discusses the uniquely human potential at it’s best when one’s predicament is turned into a human achievement. Many people with mental illness have used their creativity in music and art to bring forth a human achievement. Thus some people, who have realised that they are no longer able to change a situation such as mental illness, have appraised the situation, made certain decisions and taken action. This has been a turning point where they have focused on their strengths and creativity. Professor Boss explains how internal shifts are often linked to external control and the importance of avoiding maladjustments to ambiguous loss.

Facilitators of 9/11 programs found that meaning making was effective when it involved groups of people rather than done in isolation. Families need to be assured that it is acceptable to have different perceptions. A dialectical model of holding two opposing views at the same time and avoiding absolute ways of communicating assists family members to synthesize, compromise and avoid “scapegoating” and blaming. An important question to ask clients at this point is “What does this mean to you?” Such a question insults no culture or religion.

Making meaning is intrinsically linked to the concept of “hope” because without “meaning” there is no “hope” and without “hope” there is no “meaning”. Professor Mona Wasow’s research found that parents, people with mental illness and professionals have different hopes for recovery and that hopes and expectations of one group can influence another. She says that both hope and lack of hope has a high contagion factor. This is an important message for service providers as her research found that service providers’ grim outlook about serious mental illnesses often dim the hopes of the others or lead to a vicious cycle of low expectations and low hopes.

During my travels I was introduced to two programs; *Procovery* and *Pathways to Recovery*. In *Procovery* Kathleen Crowley draws from her own personal experiences, to show how people diagnosed with severe and chronic mental illness can heal by taking control of their lives. *Pathways to Recovery* is a project of the University of Kansas School of Social Welfare where the Advisory Group was made up predominantly of consumers. Realistic strategies on building hope are incorporated in both models. Both are self-help models based on strengths perspectives.

I recommend that the Mental Illness Fellowship adopt one of these programs as a consumer-to-consumer program to complement their current Family-to-Family program.
Symbols and rituals have the capacity to ease difficult life transitions, heal personal pain and celebrate life.

The Schizophrenia Society of Ontario and The National Alliance for the Mentally Ill (NAMI) of USA have adopted the Iris as a symbol of hope and growth, in recognition that Vincent Van Gogh, who experienced one of the major mental illnesses, painted the famous painting, *Irises*, whilst in an asylum in the south of France.

On 18th October 2005, I participated in the 7th Ceremonial Iris Planting of The Schizophrenia Society of Ontario’s Ottawa Chapter. This ceremony is in memory of those lost to mental illness and an important ritual for healing personal pain. Approximately 60 caregivers attended the ceremony. Such rituals help people recognize who they are, what they value and to come together as a community to share and acknowledge their pain.

Personal accounts from those affected and their caregivers

Whilst the Royal Ottawa Hospital in Canada currently has no programs to address the issue of loss and grief in context of mental illness, they do have a weekly group for consumers on *Coping with Illness* facilitated by Virginia Lafond. I was invited to participate as a special guest in this group where 12 people attended. When participants were informed of the reason for my visit, several participants spoke of their losses and focused on the breakdown of family relationships. One participant said she had a label attached near a light switch in her house that read:

“The soul sees no rainbows if the eyes have cried no tears”

She read this each time she used the light switch and found it comforting. When participants were asked for an alternative name for the weekly group, one participant suggested the group name: ‘This too will pass’. Participants were appreciative of the opportunity to share their perceptions of their losses.

I recommend that the family focused ambiguous loss program adopts a symbol of choice of consumers and caregivers together with healing rituals.
The Wyoming State Hospital facilitates groups focusing on loss and grief for inpatients and also for participants of the Substance Misuse Program. Groups commence with participants taking turns on reading a positive quote or poem. It is a twelve-session group, which includes video clips to stimulate emotions and cognitions, discussions on spirituality, and concludes with a healing ceremony. Participants spoke eloquently of their losses not only in relation to mental illness but others throughout their life. This often led to a stimulating discussion on how mental illness and grief affect each other. Participants spoke of how they had carried psychological injuries or vulnerabilities, which later manifested as panic attacks, depression or anger.

The Other Half Support Group in Madison is a group of partners of people with mental illness. There were 4 participants on the day I was invited as a guest. The lack of rituals and rites of passages to grieve a loss associated with mental illness was seen as a barrier to healing by participants.

Learning occurs from a variety of sources. Personal accounts of those who have experienced losses better known as “life stories” are a very valued way of learning. At the Universities of Indiana and Wisconsin, there were people in the community who had heard about my project through “word of mouth”. They requested appointments to discuss their grief with me and also to contribute to my project. My travels between the organisations in North America were by planes, trains and coaches. Invariably, my fellow travellers would ask me where I was from and what brought me to North America. When I told them that I was on a Churchill Fellowship to investigate innovative programs addressing issues of loss and grief in the context of mental illness it often lead to stimulating and interesting discussions on mental illness, losses, grief and trauma. Most people had a story to tell me of their experience of losses and grief. A number of them also had a relative or friend with a mental illness. All these highlight the importance for consumers and caregivers to tell “their stories”, be acknowledged and affirmed.

Narrative Therapy work introduced by Michael White, social worker and his colleagues in Adelaide (http://www.dulwichcentre.com.au) is widely used in The World Trade Centre Healing Service near Ground Zero, New York. According to them, “the word “narrative” refers to the emphasis that is laced upon the stories of people’s lives, and ways of re-authoring these stories in collaboration between the therapist/community worker and the people’s whose lives are being discussed”. Relatives of Police and Firemen/women lost through attempts to evacuate the buildings now conduct Tours of Ground Zero and tell their story and talk about the loved one that died. Similarly, StoryCorps (http://www.StoryCorps.net) was a project that existed in New York's Grand Central Station before 9/11 incident and is now promoted by the therapists of the World Trade Centre Healing Service. The project instructs and inspires individuals to record each other’s stories in sound. It operates soundproof booths near Ground Zero where people can record broadcast-quality oral-history interview with loved ones or friends. A trained facilitator helps them develop a question list and handles all technical aspects of the recording. An example is an immigrant telling a friend about the challenges
she faced coming to America. Relatives of those who went missing following 9/11 are encouraged to record their story about their loved one.

Listening to "life stories" also highlighted for me that healing of loss came through different ways. For some it was through reading fiction or non-fiction. For others it was through music or art. Most said that the benefits of speaking to a "stranger" was that there was no pressure for them to find solutions for their losses nor was there any pressure for “recovery”. People simply wanted to tell me “their story”. These findings suggest that family focused ambiguous loss programs will be most effective if separated from recovery programs.

I recommend that family focused ambiguous loss programs are separated from recovery programs.

Conclusions

In my work with people with mental illness and their families, I have observed many different emotional and physical responses to the illness, which I have interpreted as simply a normal reaction to loss. It is important that service providers do not interpret these responses as a medical condition or dysfunctional behavior. It is not unusual for people to experience depression, anxiety, ambivalence and relational conflict due to unresolved grief and distress from having a family member partly gone and partly here. Consumers and caregivers need to be encouraged to resist social pressure to “get over” the loss but given skills to live with the ambiguity by developing resilience based on personal strengths and family and community support.

I believe it is important to address the losses within a family context as these losses have the potential to affect family relationships and cause division. Research findings suggest that the onset of mental illnesses such as schizophrenia and mood disorders is almost always in young adulthood and as such the repercussions of family breakdown have long lasting consequences. The goals of interventions are to minimize the degree of distress, promote resilience and family connections.

Community participation and empowerment is an important aspect of the development of family focused ambiguous loss programs. I therefore believe the development of a pilot program need to be in partnerships with Mental Illness Fellowship and ARAFMI Mental Health Carers and Friends Association of West Australia.

I also believe that the family focused ambiguous loss program be dedicated to addressing issues of loss and trauma only and not focused on recovery nor symptoms and signs of mental illness. There are very effective recovery programs for those diagnosed with the illness being facilitated both in government and non-government services and should not be duplicated.

Although there are programs addressing loss and grief of mental illness for consumers or caregivers, to the best of my knowledge there are no programs
addressing the ambiguous loss associated with mental illness within a family context that includes both the person diagnosed and his/her family either in Australia or any other country. The importance of such a model was acknowledged by all of the agencies that I visited. My proposal provides North Metropolitan Health Service in West Australia to take the opportunity to develop an innovative and comprehensive family focused ambiguous loss program in the context of mental illness that has the potential to be internationally leading. If implemented, the program will be evaluated both quantitively and qualitatively. Findings and knowledge gained will be shared through contribution to international professional journals. The knowledge and experience gained will also be valuable in other situations of ambiguous loss.

**Recommendations**

To minimize the distress and trauma experienced by those affected by mental illness and their relatives and promote resilience and family connectedness, I recommend:

1. Raising awareness of the concept of “psychological ambiguous loss” with consumers, caregivers and service providers of mental health services.
2. In partnership with consumer and caregiver organizations in West Australia, develop a family focused program on ambiguous loss, to complement the new Carers’ Recognition Act of Western Australia.
3. Offering alternative modalities of non-verbal treatment as part of the family-focused ambiguous loss program.
4. Developing formal training opportunities of therapeutic work with Ambiguous loss for service providers in mental health services and other related services.