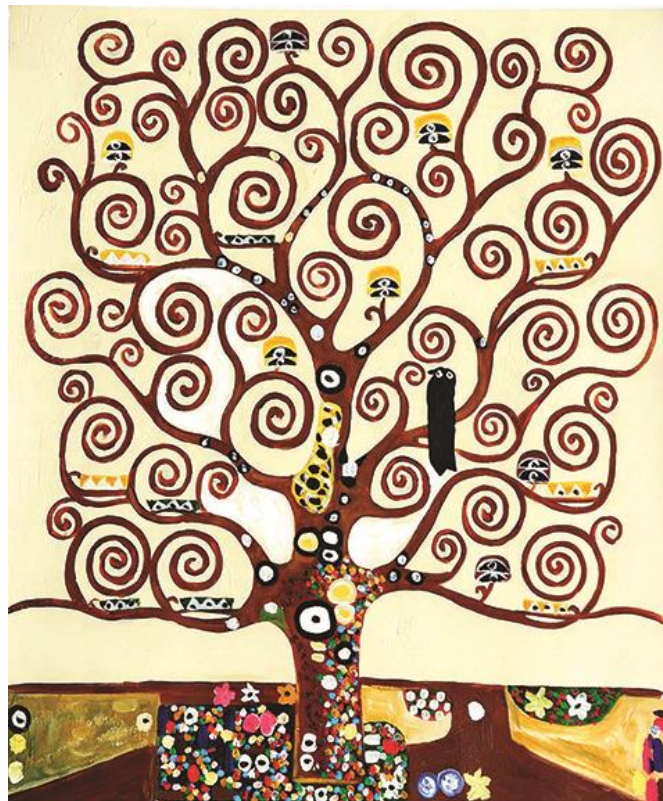




Supporting the Informal Caregiver

NYU Caregiver Intervention

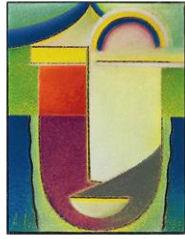
Interview with Dr. Mary Mittelman



Based on Gustav Klimt, Tree of Life, Stoclet Frieze, Lebensbaum, 1905

By Jean Galiana
ACCESS Health International

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Elder and Long Term Care

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Background

The NYU Caregiver Intervention is an evidence based program that provides support to spouses, partners, and families who are caring for a relative with dementia. Dr. Mary Mittelman and the expert clinicians in her NYU School of Medicine laboratory developed and tested the intervention for more nearly thirty years. In the past decade, there have been many community translations of the NYU Caregiver Intervention. To meet the demand for trained counselors, Dr. Mittelman and her team have created an online training course for social workers and other social service clinicians to become certified in the intervention so they can bring it to their organizations or communities. The basic training is a ten hour course. If the learner watches all of the case studies in full, the course takes twenty fours.

Research on the intervention began in 1987 when the National Institutes of Health funded a randomized controlled trial. The researchers found the caregivers in the treatment group experienced fewer symptoms of depression, were more satisfied with the support they received from family and friends, were less reactive to the behavior of the person with dementia, and were physically healthier than those in the control group who received the usual care provided in the laboratory at NYU. These changes enabled the caregivers to keep their spouse or partner with dementia at home with them for an average of a year and a half longer than those in the control group. They also coped better when their loved one moved into a nursing home or passed away.

During the research period, counselors responded to caregivers in the control group when they asked for assistance. However, those in the control group did not receive the six individual and family counseling sessions that participants in the treatment group received. The researchers concluded that mobilizing family support is the single most important factor in caregiver well being.

Most often caregivers wish to keep their older relative with dementia at home as long as possible.

The components of the intervention include individual and family counseling, recommendation of support group participation, and ad hoc counseling as needed. The individual and family counseling sessions occur within four to six months of a comprehensive intake evaluation. Counselors offer support throughout the entire course of the caregiving process and up to two years after

the death of the person with dementia. The counseling has elements of coaching and sometimes mediation with the caregiver's family. The counseling is individualized to the caregivers' needs and desires. Most of the time, these desires include being able to keep their family members with dementia at home, rather than putting them into a residential care facility.

Caregivers, particularly if they are the spouses or partners of the person with dementia, often become isolated from family and friends. They may avoid the company of others because of the stigma associated with the illness. They may also not know how to ask or what is reasonable to ask of family and friends. Even well meaning family members may not know how to interact with the primary caregiver in a constructive and supportive manner. Caregivers often wait to seek help until they or their relatives with dementia are in crisis. They are regularly put in the position of making choices without sufficient knowledge about dementia and the best options for care of the person with the illness or of themselves.

The individual and family counseling sessions in the NYU Caregiver Intervention focus on improving social support for the caregiver by enhancing the positive aspects and reducing the negative aspects of family interactions. The intervention provides education, as needed, about the causes and possible responses to the symptoms of dementia that the caregiver's relative may experience as the disease progresses. Counselors help the caregiver and family members to develop a plan for sharing the care now and in the future. During the study period, the intervention was provided with federal grant funding and was free to caregivers.

In the fall of 2015, New York State Governor Andrew M. Cuomo awarded a five year, seven and a half million dollar grant to NYU Langone Medical Center to launch the Family Support Program. The program provides support, counseling, and referrals to community resources for those in New York City who are caring for a relative with Alzheimer's disease and related dementias. The funding for ten such programs throughout New York State is at least in part due to the research and proven outcomes that provided an evidence base for the effectiveness of counseling and support interventions like the intervention developed by Dr. Mittelman and her team. Dr. Mittelman said "This grant provides a unique opportunity to enact a model of the best possible care and support services for those caring for people with Alzheimer's disease. These caregivers face an

incredible burden to their own mental and physical health as they provide care for their relatives affected with dementia.”

The outcomes of the studies of the NYU Caregiver Intervention have been widely published in peer reviewed journals. In the past decade, there have been many government supported translations of the intervention by communities in the United States, as well as new randomized controlled trials. The article “Translating Research into Practice: Case Study of a Community-Based Dementia Caregiver Intervention” details the challenges and outcomes of the implementation of the NYU Caregiver Intervention at fourteen sites in Minnesota.

A report by Act on Alzheimer’s describes a research model that estimated the economic impact on the state of Minnesota if at home caregivers for those with dementia participated in the NYU Caregiver Intervention. Among other projections, the researchers estimated that if thirty percent of the caregivers were to participate in the intervention, the state would save as much as one and one quarter of a billion dollars in direct healthcare costs between 2010 and 2025.

A report by the University of Pittsburgh Health Policy Institute calls for evidence based policy change at the state and federal levels to support family caregivers. The report acknowledges the benefit of caregiver support and suggests that there are not enough of such programs to meet the expanding need

Dr. Mittelman also founded The Unforgettables Chorus. The New York City based chorus is made up of people with dementia and their family members and friends. The chorus gives members the chance to get out and enjoy learning to sing and perform together. It also serves as a social support for the caregivers. As they rehearse and perform regularly for the community, caregivers are able to interact with others like themselves in a normal environment. The chorus has been featured in publications including The Huffington Post, The New York Daily News, and The National Herald (an online Greek newspaper). It has also been broadcast by news programs including ABC News and PBS. Dr. Mittelman hopes to expand the number of choruses like the Unforgettables. She also plans to conduct a rigorous study of its benefits to both the participants with dementia and their caregivers.

In this interview, Dr. Mittelman discusses the NYU Caregiver Intervention from its inception to how it has evolved over nearly thirty years. She also details her plans for additional innovative caregiver interventions.

About Mary Mittelman



Mary S. Mittelman is a Research Professor in the Department of Psychiatry at the New York University School of Medicine. She is an epidemiologist who has been developing and evaluating psychosocial interventions for people with cognitive impairment and their family members for more than three decades. For more than twenty years, she was Principal Investigator of the National Institutes of Health funded study of the NYU Caregiver Intervention. The results of the intervention have been published widely.

Dr. Mittelman has won many awards including the first global award for psychosocial research in Alzheimer's and dementia. The NYU Caregiver Intervention was named "the best evidence based intervention for people with dementia and their carers." The award was granted by the Alzheimer's Disease International and Fondation M d ric Alzheimer. Dr. Mittelman and her colleagues have developed online training for social service professionals as well as a telehealth version of the NYU Caregiver Intervention.

In the past decade, Dr. Mittelman has also been evaluating and developing interventions that include the person with dementia together with the caregiver. She is the founder of a chorus for people with dementia and their family members called The Unforgettables. The chorus rehearses and gives regular concerts at Saint Peter's Church in Manhattan.

Interview

Jean Galiana (JG): What inspired you to start the New York University Caregiver Intervention?

Mary Mittelman (MM): My initial motivation, as well as the motivation of most of the people I know who are involved in family caregiver work, is that we had a relative or friend with dementia. And it is likely that many of us will also have dementia one day.

I am a psychiatric epidemiologist by training. I drafted a grant proposal to study families. I sent it to Steven Ferris who was the head of what has now become the Alzheimer's Disease Center here at NYU. He introduced me to four women who had developed strategies to help family caregivers. They were talking to and helping the caregivers while the people with dementia were being evaluated. I said to these four women, "What do these people all have in common?" They said, "Nothing." I said, "Well, I am an epidemiologist. I want to draft a grant proposal to test whether what you have been doing is effective." I needed a theme. "What do they have in common?" They insisted that there is not a specific theme that caregivers have in common. I decided that they knew more than I did and that the theme should be "every caregiver is different." This meant that, to be effective, an intervention has to be individualized to each caregiver's strengths, weaknesses, and needs.

I formalized and created a structure for the caregiver intervention that the clinicians at NYU had been providing and drafted a grant proposal in late 1985. It was funded to begin in August 1987. The National Institute of Mental Health originally supported it. The National Institute on Aging took over the funding in 1991. The proposal was to conduct a randomized control trial of caregiver counseling and support in a formalized way. We began with a comprehensive assessment to get a profile of the caregiver and of the person with dementia for whom he or she cared. In the initial study, all the caregivers were spouse or partner caregivers. Over a period of nine and a half years, we ended up enrolling four hundred and six caregivers. The first cohort was 206 couples. I then received a second grant and enrolled two hundred more. I started out with a four year grant and I ended up with over twenty years of funding sequentially.

We followed some of these caregivers for as long as eighteen years. We had less than a five percent dropout rate while the person with dementia was still at home,

which is extraordinary in an older adult population. Most of the caregivers were also older adults since they were spouses or partners. I attribute the low dropout rate to the fact that even the control group received a lot of support. The intervention had some structured and some unstructured components. There was the evaluation. Then the caregivers were randomized. Those in the treatment group had six individual and family counseling sessions. It began with an individual session for the spouse or partner caregiver, four family sessions, and then another individual session followed.

JG: How many of the caregivers' family members participated?

MM: Two or more. We had as many as thirteen. We consider family to be anyone who the caregiver considers to be family. Caregivers are not necessarily relatives. Caregivers can be best friends, if they feel like family. We never had children under eighteen, but sometimes we had three generations in one room. Certain cultures had bigger families on average than others.

After the first individual session, there were four family sessions, and then there was another individual counseling session. Then we did a follow up assessment, at which time we urged the caregivers to join support groups. The counselors were available to the caregiver and the family any time they needed help. The counselor would hand out a card to every family member. At the beginning, ad hoc counseling was not explicitly defined as part of the formal counseling. We noticed people were calling the counselors when they needed additional advice, referrals and support, and that they often commented on how important a resource this was. So we added it as a formal component of the NYU Caregiver Intervention, calling it “ad hoc counseling.” Even if caregivers did not call, they would often say at the follow up, “I did not think I could cope and then I remembered I had your card. I was able to cope because I knew I could call you. The card is like a life preserver.”

Because of the human nature of the program, there was no way we could stop people from getting help. The non placebo control group would often call the counselors. When they came in with a person with dementia they often would seek out the counselors. The one component that they did not get was the family counseling. For that reason, we came to believe that the family involvement component was the potent part of the package.

The package as a whole is crucial. For example, you cannot provide family counseling alone, even though it is the most potent ingredient. A report in PLOS

ONE details the efforts of one organization in the Netherlands that attempted to use the family component on its own, and to space the sessions over a one year period. It did not work. The NYU Caregiver Intervention is a package and each part of the package has a contribution. It is like baking a cake. You cannot take an ingredient out and get the same cake. If you did, you would make a different cake.

Each part of the counseling was individualized and devoted to what the participants said they needed. The counselors always tried to make a point of helping the caregiver to understand the importance of involving their families. Before anything was ever published, there was one female caregiver who appeared on *Eyewitness News* with Emma Shulman and me. Emma, with whom I shared an office for about five years, worked with me until she was ninety eight. She and I and the caregiver were all invited. During the interview, I overheard the caregiver say that she would never have survived without the counselor.

I remembered that caregiver was in the control group. I was worried that, if she was so grateful, there would be no difference in outcome between the treatment and control groups. Then, a few months later, she placed her husband in a nursing home. We had questionnaires for everything. We asked her why she placed her husband in a nursing home. She said, “My sons never helped me.” The one component she did not receive was the family counseling. So, do we know whether she asked for help and whether her sons would have helped her if she asked? There are any number of reasons why family counseling can improve the situation. In some families, the caregiver will say, “They ought to know enough to offer. I shouldn’t need to ask.” Other caregivers will say, “They have their own lives to lead. They should not be bothered. I am going to do this by myself.” Other caregivers keep completely hidden.

Social support is the mediator of all the other outcomes that we found. Compared to the control group, which received much more than a placebo, the caregivers in the treatment group had fewer symptoms of depression. They had much less severe stress reactions to the patient’s behavior despite the fact that the patient’s behavior did not change. They had better self rated health. These outcomes led to the ensuing outcome that the government loved. We postponed nursing home placement for a year and a half longer among people whose caregivers were in the treatment group than among those in the control group. Satisfaction with social support, with emotional support from family and friends, with assistance from family and friends, and the number of people to whom the primary caregiver felt close, made the difference. Those were the mediators of all the other outcomes.

Once I had demonstrated that the intervention was effective, I felt like, while it is not a university professor's job, it was my job to make it available as widely as possible. Most people who work in university life focus on getting tenure and promotions and more grants. I think I probably sacrificed some of that because I focused on making the intervention available.

The intervention was written about in peer reviewed journals. But those readers are not the people the intervention supports. Our challenge was to connect the intervention to the millions of people whom it could support.

The next development was that people started to implement the intervention in the way they thought it was supposed to be done but not the way we designed it. They were not getting the same results, because they were not doing it properly. That is when we knew we had to publish the intervention process in detail. So we wrote a book entitled *Counseling the Alzheimer's Caregiver: A Resource for Health Care Professionals* that was published by American Medical Association Press in 2003.

JG: It must be disappointing when you hear of other organizations doing only part of the intervention.

MM: Yes. One organization in the Netherlands decided they would just conduct the family part of the intervention. They conducted one family session every three months but measured outcomes after every four months. After one year, they had no positive outcomes to report. I finally said to the principal investigator of this grant, "If you were told to give your child penicillin every six hours and you thought you would space it out differently and give it to them once a day, do you think you would get the same outcome?" We were concerned that organizations would not do the intervention properly.

This is what spurred us to develop a formal online training course. We received a Small Business Innovation Research grant from the National Institute on Aging to develop the detailed training. We created the training program with Healthcare Interactive. The training included specific and extensive videos of case studies as well as text and video commentary. Now, any organization in the world can train their staff how to do the New York University Caregiver Intervention properly and in its entirety.

We developed that training and then we did a cluster randomized control trial of the training. I reported at the Alzheimer's Association International Conference

last year in Washington that the randomized control trial showed no difference in knowledge of the intervention and understanding of it between clinicians who received the training in person and those who received it through our online program. The online training has some value over the in person training that we were doing before because you can have it in the middle of the night, you can have it on the weekend. If you lose one employee you do not need me to return to train the replacement.

JG: Please describe the pilot program you conducted in Minnesota.

MM: In approximately 2007 or 2008, the Administration on Aging started to send out calls for states to apply for funding to conduct trials of evidence based interventions. Minnesota was the first to conduct a translation of the NYU Caregiver Intervention. You may have seen the Health Affairs article, *Translating Research into Practice: Case Study of a Community-Based Dementia Caregiver Intervention*. They enrolled 280 caregivers. California, Georgia, Wisconsin, Florida, Virginia, and Nevada also received funding from the Administration on Aging to conduct what they call “community translations” of the NYU Caregiver Intervention.

In addition, the Rosalynn Carter Institute for Caregiving funded pilot studies in Vermont, Nevada, and at an agency that provides care for the homebound in New York City. We also conducted the Three Country Study in Australia, the United Kingdom, and the United States. The study demonstrated outcomes similar to the original study, significantly reducing caregiver depression.

I realized that there were many caregivers who could not access the intervention either because they live nowhere near an experienced counselor or because their families are spread widely. I am committed to making the principles of the intervention available to as many caregivers as possible. I started thinking about rural caregivers and the many other factors barring people from getting counseling in person. They might live in Staten Island or Brooklyn and not be able to get here. They might not like driving at night and their children are only available at night. We started getting requests to include family who were living in different states. They wanted to participate by phone. I heard it a couple of times and I thought, “We should do this intervention using video conferencing.”

We developed a videoconferencing version of the intervention. It is only different in the sense that people do not need to be in the same room to participate. We use Zoom, which I chose because several people with dementia were using it to

make conference calls and thought, “If they can do it, we should use it.” We will be able to reach many more caregivers with this technology.

We are now doing a randomized control trial to compare the online version of the intervention to counseling on the phone. I do not want to be selling it if it does not have an evidence base behind it. I just found out this morning we have twenty eight caregivers enrolled in the randomized control trial. We are hoping to have a total of 240 by the end of the year. We have counselors in many states now that are enrolling caregivers.

JG: How many organizations have implemented the initiative already?

MM: I think there have been fourteen translations and new randomized controlled trials. We recently concluded a trial in Israel that has yielded similar results to the research at NYU. Those results are soon to be published. We are also working in Paris with Saint Joseph hospital. And we are hoping to implement the intervention elsewhere in France. To me, there is no limit.

JG: Is the intervention training available in languages other than English?

MM: The intervention training is available in English. We simultaneously developed it for Australia with a small grant that the University of Queensland received. I was a consultant and my colleague had a subcontract. With that grant, we translated the words that were not Australian. For example, “caregiver” became “carer.” The training is narrated by a native Australian. A year after we started training people in Australia, we videotaped one of the counselors who had the most experience providing live counseling with an Australian family. We have all the sessions, the evaluation, the individual and family counseling with an Australian family available in the online training. Families are different. Cultures are different. Expectations are different. And language is different. That is why we customized the training to be specific for Australia.

JG: Do you plan to bring the intervention to other countries as well?

MM: Yes. But I also would like the training to be culturally relevant. We should begin by offering the existing training and then translate it into the culture. We would accomplish this by training people who speak English and the native language of the country. It is not a matter of simply translating the language. We would need to understand other culturally relevant issues for caregiving in each country.

JG: Have you advocated for policy change in order to get the intervention reimbursed by insurers?

MM: I think our reliance on drugs and what doctors traditionally do is not sufficient for chronic care and for illnesses like those that cause dementia. As a culture, we do not value support programs like the New York University Caregiver Intervention. It is time that insurers understand the importance of treating the caregiver, especially in the absence of disease altering medications. Helping the caregiver can save a lot of money in physical and mental healthcare costs for the caregiver. We do not think about that as often as we should. We have also mentioned the cost savings realized for the person with dementia because, with the caregiver intervention, the person can remain at home for an average of a year and a half longer.

I met with the Centers for Medicare and Medicaid Services. They recommended looking for an opportunity to have a managed care company conduct a pilot test so that we could prove that we are saving healthcare costs, not only for the person with dementia but for the caregivers among their insured.

We need to find the right connections and legislative backing. There is a letter circulating in the senate about caregiver interventions now. The letter mentions the New York University Caregiver Intervention and one other. There is evidence behind both of them that makes a clear case for providing interventions for the benefit of the patient as well as the caregiver.

JG: Please describe the grant that NYU recently received from the state.

MM: That was an exciting grant for us. In the fall of 2015, New York State Governor Andrew M. Cuomo awarded a five year, seven and a half million dollar grant to NYU Langone Medical Center to launch the Family Support Program that provides support, counseling, and referrals to community resources for those caring for a relative with Alzheimer's disease and related dementias throughout New York City.

JG: Are you designing additional caregiver support interventions?

MM: We think that older adults with other chronic illnesses, like multiple sclerosis for example, could also benefit from this kind of intervention. One of my best friends died with multiple sclerosis. I think the family would have benefited from a similar family intervention. We have also submitted proposals to design

and evaluate interventions based on the same paradigm for traumatic brain injury.

We have a couple of innovations that we are including in our new five year New York State funded Family Support Program, in which we will be providing caregiver support in the five boroughs of New York City. Darby Morhardt at Northwestern University developed the Buddy Program, where first year medical students become companions of people in the early stage of dementia. We plan to expand that model here so that students in all the schools at New York University will be buddied with people in the early stage of dementia. They have things to teach each other. This program will also provide respite for the caregiver while the student is with the person with dementia. The students and the people with dementia will have an invaluable experience. Someone from the engineering school asked me what an engineering student could get out of this experience. I replied, “The engineer might be designing products for older adults with impairments. Why not have an older adult to talk to so they have a better idea of what would work?”

We also plan to add a peer mentoring program, which has already been successful in other contexts. We are going to engage people who have experience being a caregiver for a long time, to mentor other caregivers. The mentors could have lost the person with dementia, or just have time available. They may wish to share their experiences and what they learned about how to get the help they needed. The mentors may offer ideas to make the new caregiver feel more comfortable about talking about being a caregiver to their family and friends. If they do not talk about their situation, they can become isolated and overwhelmed. I have already asked two of the people who are in The Unforgettables chorus who have lost their partner with dementia. And they both want to be peer mentors.

We will be looking to connect with and provide counseling and support for the caregivers who, either because of the stigma of the illness or for other reasons, are trying to keep the dementia diagnosis secret. Perhaps they do not want to acknowledge the diagnosis themselves. I want to find those caregivers, to help them reduce their stress and isolation. I want to make it possible for caregivers to discuss their situation with the peer mentors and, ultimately, with their family and friends.

JG: How many caregivers do you serve in your new program today?

MM: With the New York State funding, we are hoping to serve six hundred caregivers in our new program annually.

JG: Is there anything else that you would like to share?

MM: I think everyone is interested in research on drug trials and how drugs can improve cognitive function. I think that we should be equally concerned with wellbeing and quality of life. Even in the face of functional or cognitive decline, people can have a good quality of life if we provide them and their caregivers with appropriate support. That is why we started the chorus for people with dementia and their family members. We found that people even in the middle stage of dementia can learn new songs and can perform together with their family members for the joy of the community. Their quality of life is arguably much better because they have these activities.

JG: Thank you for this interesting discussion.

MM: Thank you for your interest in our efforts to develop, evaluate, and disseminate psychosocial interventions that can improve the wellbeing of family caregivers, and the people with dementia for whom they care.

END