

Counseling and Support Can Reduce Emotional, Physical and Financial Costs of Dementia A Vision for International Expansion of an Evidence-Based Intervention



“Everyone is interested in research on drug trials and how drugs can improve cognitive function. I think that we should be equally concerned with well-being and quality-of-life for those with dementia, their caregivers, and their families.”

Mary Mittelman, DrPH
Developer of the NYU Caregiver Intervention
Research Professor, Psychiatry and Rehabilitative Medicine
NYU School of Medicine, NYU Langone Health

The Problem

Alzheimer’s disease has devastating effects on both patients and on the families who care for them. Drugs produce only modest improvements and the possibility of curing or preventing Alzheimer’s disease remains far in the future. In the meantime, as the population continues to age, the financial and emotional cost to patients and families as well as the cost to the federal health care budget continues to grow. This problem is growing more quickly in developing countries than in industrialized countries. While new pharmaceutical interventions may provide more benefits than those that are currently available, they are likely to be expensive, and may be unaffordable by many families dealing with dementia. In addition, migration of young adults to cities or from other countries to the United States while older family members have remained behind, means that family caregivers are often widely dispersed

A Potential Solution

The NYU Caregiver Intervention (NYUCI) can be provided to caregivers at relatively low cost, particularly in countries where wages are relatively low. The intervention has demonstrated multiple benefits over the past 30 years. Online training in how to conduct the NYUCI both in person and via videoconferencing is available. The NYUCI can be used in combination with pharmaceutical intervention, and provides additional benefits. The nihilism among physicians, who avoid diagnosing dementia because there is currently no drug that can slow or reverse the progression of dementia could be counteracted by more widespread knowledge of the power of psychosocial interventions like the NYUCI. If there are more patients diagnosed, there are more patients potentially available for clinical trials of drugs to treat AD.

The Goal of the NYUCI

The goal of the NYUCI is to improve the well-being of family caregivers, and thereby to enable them to keep the person with dementia at home longer than would otherwise have been possible. The main mechanism for improving caregiver well-being is improving social support, largely through helping the caregiver and other family members to interact in positive ways, but also by

providing referrals to appropriate resources in the community. Because every family has different needs, the intervention is individualized. counseling. Because most caregivers would benefit from more understanding and help from their families, the intervention includes family counseling. Because Alzheimer's disease can last for many years and its effects change over time, the intervention is not time-limited.

What is the NYUCI?

The NYUCI, developed at the NYU School of Medicine, in New York, USA, is an evidence-based multicomponent intervention that provides counseling, education and support to family caregivers of relatives living with dementia, either in person or via video conferencing. It includes individual consultation, family consultation, and 'ad-hoc'—additional phone or video telecounseling as needed—for primary caregivers and other family members.

The Components of the NYUCI

When they enroll, , caregivers receive a comprehensive assessment of their needs, strengths and resources, the support they receive and would like to receive from family members and friends, and their emotional and physical health. They then have six consultations over a four month period. First, they have an individual consultation with a trained counselor, to further explore their needs and encourage them to think about the family members they would like to include in the following sessions. There are then four consultations with family members selected by the caregiver. Then there is an individual session to discuss what has been achieved, and what issues still remain and how to potentially address them. A vital component of the intervention is that counselors continue to provide what we call ad hoc counseling, which is consultation and support for caregivers and their families for as long as needed usually on the telephone or by email. Thus, counselors are available to help caregivers and their families deal with crises and with the changing nature of the patient's symptoms, to provide information and referrals for additional help, and help them understand and manage their reactions to the patient's behavior. Caregivers are also encouraged to join support groups that met regularly, as an additional source of ongoing information and support from their peers. The NYUCI received the first global award for psychosocial interventions from Alzheimer's Disease International/Foundation Mederic Alzheimer.

The Initial Study of the NYUCI

The NYUCI was first evaluated in a randomized controlled trial, which began in 1987 and lasted for more than 20 years, with funding from the National Institute of Mental Health and the National Institute on Aging (NIA). More than 400 husbands and wives of patients with Alzheimer's disease enrolled in the original study over a 10 year period, beginning in 1987. Some stayed in the study for as long as 18 years. The exceptionally long duration of the study made it possible for us to assess both the short and the long term effects of the intervention. The study was a randomized controlled trial, in which participants either received the NYUCI, or the usual care available to caregivers at NYU at the time.

Evidence of Benefits

The beneficial effects of the NYUCI have been well documented in peer-reviewed journals. The initial 20-year randomized controlled trial demonstrated that the NYUCI had long lasting benefits; caregivers were more satisfied with the support they received from family and friends¹, experienced fewer symptom of depression², were less reactive to dementia-related behaviors³ and

were physically healthier than those who received usual care⁴. As a result, caregivers who received the NYUCI were able to keep the person with dementia at home for an average of a year and a half longer than those who received usual services⁵. These benefits were largely achieved through improving social support – the number of people to whom the caregiver felt close, and the caregiver’s satisfaction with emotional support and with assistance from family and friends⁶. Many additional randomized controlled trials and successful community implementations of the NYUCI in the United States and abroad, in England, Israel, and Australia have achieved similar results.

The Benefit of the NYUCI for Caregivers of People Receiving a Drug for Dementia

In the Three Country Study (US, UK and Australia, all participants with dementia received donepezil, one of the drugs that are currently available to mitigate some of the symptoms of dementia, while half the caregivers in each country received the NYUCI. We demonstrated that the caregivers who received the NYUCI became less depressed over the two year period in which they participated in the study.⁷ This suggests the potential greater power of a combination of drug plus psychosocial intervention for maximum positive effect.

An Example of a Community Implementation of the NYUCI

Evidence of the effectiveness of the NYUCI led the Administration on Aging to fund translations of the NYUCI in six states—Minnesota, Florida, Georgia, California, Wisconsin, and Utah—through the Alzheimer’s Disease Supportive Services Program. Minnesota was the earliest, and the longest-running, implementation and included 228 caregivers. The implementation of the NYUCI in Minnesota was associated with improved outcomes in multiple key domains for caregivers of people with dementia that have critical clinical and public health implications. Consistent with the original study of the NYUCI, assessments showed decreased depression and distress among caregivers. Participating in a greater number of caregiver counseling sessions was also associated with longer time to nursing home placement for the person with dementia. Given the challenges faced in the community setting, web-based training for providers and video-conferencing for caregivers may be a cost-effective way to realize the maximum benefits of the intervention for vulnerable adults with dementia and their families.⁸

The NYUCI in Israel

A recently completed randomized controlled trial in Israel was the first to confirm the effectiveness of the NYUCI in a non- English speaking country, especially its long-term effects in reducing depression. As a consequence of the study’s positive results the NYUCI is now being implemented by many municipalities across Israel.

The Cost Savings

The potential cost savings from keeping people with dementia out of expensive institutional care for a year and a half are substantial. A model of the economic impact of the NYUCI estimated that the state of Minnesota (with a population of only 5.5 million) could save as much as \$996,000,000 in direct healthcare costs in 15 years if all caregivers for those with dementia participated, solely due to lower rates of institutionalization.⁹ Potential direct cost savings to Medicaid were also substantial.¹⁰ By improving the physical and emotional well-being of caregivers, the NYUCI undoubtedly achieves additional healthcare cost savings.

Issues in Expansion to Developing Countries and Potential Solutions

- Not every health professional has access to telemedicine capabilities for training in providing the NYUCI, but some will and can transmit the information they receive to others. Furthermore, the content of the training can be put on DVDs, which could be distributed to those who do not have internet access.
- Many people in developing countries are poor, and many of them work at home, which makes it difficult to provide care for a person with Alzheimer's disease at home. Others leave the person with dementia alone at home in order to go to work. There are very few, if any, institutions to provide patient care outside the home. A program of training for home care workers could be developed in tandem with training of professionals to provide the NYUCI. Thus paid help (which could be other relatives) could supplement the efforts of the primary caregiver. This could provide jobs as well as help to meet caregivers' needs.
- Traditional healers provide ongoing health care in many in rural areas using "home remedies," and are respected by their clients. Unless they are made part of the process of disseminating and providing the intervention, they may interfere and oppose new treatment strategies such as the NYUCI. They should be given the opportunity to learn about dementia and its effects on caregivers, and about the potential effectiveness of interventions like the NYUCI. Perhaps they should also be trained to provide the intervention. Traditional healers in Africa have a continental association that could be worked with on this.

Vision for International Partnerships to Make the NYUCI Widely Available

International availability of the NYUCI will have a global impact on the cost and care of people affected by Alzheimer's disease, helping families with the proven benefits of counseling and support. We have developed and tested an online NYUCI training and certification program for professionals that can be translated into any language. The online training in providing the NYUCI in person and via video teleconferencing can further be embedded, in whole or in part, in educational courses to make this effective psychosocial intervention culturally relevant, scalable and widely available. The NYUCI has been implemented by mental health providers such as social workers, nurses and psychologists. We recognize the importance of the context of caregiving, health care policy and service delivery and therefore would want to partner with stakeholders in developing a linguistically and culturally specific training program based upon local needs. Our 30 years of experience in providing, studying and creating training materials for the NYUCI has given us unique expertise in how to operationalize its essential core concepts and yet remain flexible to specific culturally appropriate realities in each setting.

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