


Supporting Individuals and Families Impacted by Dementia in Counseling: Case Report

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Kathy Lee, PhD, LMSW¹ , Jamie English, LCSW-S, CEDS²,
and Venieca Kusek, LMSW³

Abstract

As more than 6 million people in the United States are living with dementia, it is important to foster and train counselors who are specialized in dementia. This case report explores the process and benefits of counseling when individuals and families are impacted by dementia. By understanding multiple changes in the individual and the family system, a counselor can provide guidance and resources to navigate and adapt changes during the disease process. Based on family systems therapy, a counselor can assist the family by facilitating family involvement and communication. It is critical for a counselor to help the family members in understanding how each one may be in a differing stage of acceptance regarding the diagnosis and loss. In addition, dementia-specific counseling should entail psychoeducation of the disease as well as existing community-based resources that are designed to support community-dwelling people living with dementia.

Keywords

caregiving, communication, geriatrics, patient education

Introduction

Individuals living with dementia suffer from memory loss, deteriorated language skills, and personality changes (1–5). People who have been diagnosed with dementia can benefit from counseling by learning to adapt to these changes in their lives. Family caregivers can also benefit from counseling. A counselor can guide family caregivers through the challenges and help them process emotional frustrations that come with their caregiving work (5,3). As 80% of people with dementia are receiving home-based care from their family members (6), the family systems are particularly affected by a loved one's cognitive declines. Structural family theory is often used in practice to capture repetitive patterns among family members for communications, disagreement management, and positive and negative relationships with one another (1–3). By understanding family interactions and family functioning, a counselor could help family caregivers' distress and support them to not only resolve family conflicts but also adapt changing caregiving needs and caregiver-care recipient roles during their caregiving trajectory (3). While counseling is commonly suggested to reduce sadness, stress, or caregiver burnout (5), dementia-specific counseling can be designed to highlight

the importance of communication between family members and structural changes in roles and expectations (1). In addition, dementia-specific counseling can help improve the knowledge of the disease and existing community-based resources. Psychoeducation is effective in knowledge transfer (eg, illness and treatment process) as well as emotional support, which has been evidenced to be helpful for treatment adherence (7). In this case report, we provide an example of counseling using family systems therapy and psychoeducation and share lessons learned from this experience.

Description

The client's name is Morgan (a pseudonym), female, 64 years old, and married. She was diagnosed with

¹ The University of Texas Arlington School of Social Work, Arlington, USA

² Inner Revolution, Grand Prairie, USA

³ Angel Care Hospice, Richardson, USA

Corresponding Author:

Kathy Lee, School of Social Work, University of Texas at Arlington, 211 S. Cooper St. Arlington, TX 76019, USA.
Email: kathy.lee@uta.edu



Alzheimer's disease by a geriatric medical doctor one month prior to seeking therapy. She is with her husband of 20 years and 2 children from her previous marriage. Her daughter who is a nurse has been playing a critical role in supporting Morgan by arranging all of the necessary medical appointments. She also held a family meeting to reveal Morgan's diagnosis and continued to discuss plans for her disease progress with other family members.

Over the past couple of years, Morgan and her husband, Patrick, experienced some adverse life events. They unexpectedly lost Patrick's son to a tragic accident. In addition, Morgan was laid off from her employment due to constant mistakes that she made potentially due to her cognitive declines. Patrick dealt with severe arthritis and went through two surgeries which prevented him from working for a while as a plumber. Collectively, the couple was facing financial challenges which were further complicated by Morgan's age. Being 64, Morgan was not eligible for Medicare, and she did not have health insurance after she was laid off. Each session, Morgan was accompanied by one of the family members (eg, husband, daughter, son, and daughter-in-law). Counseling was led by the first author and supervised by the second author. Each session was reviewed by all the authors. The client provided written informed consent.

Results

Explaining the Disease

Various researches show people's lack of understanding of dementia (8), particularly limited knowledge of risk factors related to the disease (9). Even though Morgan and her family were able to learn about Alzheimer's disease during the initial diagnosis, they still struggled to understand dementia symptoms and treatments. The first session focused on understanding the client and her family dynamics and providing brief information about dementia. The following session focused on providing more information to supply them with necessary knowledge about the disease: (1) signs and common symptoms of Alzheimer's disease, (2) stages of the disease, (3) social and behavioral factors affecting the disease, (4) diagnosis process, and (5) primary (eg, reducing risk-factors), secondary (eg, timely diagnosis and intervention), and tertiary (eg, reducing comorbidities and disability) preventive efforts that they could make (10, p. 216).

Sharing Resources

Despite Morgan's family members being resourceful and proactive to support her, they were not aware of resources in their community, including a local chapter of Alzheimer's Association. During the sessions, the 24/7 Helpline information was provided for the family which they can call anytime for a question regarding the disease. In addition, existing virtual and in-person support groups

offered to family caregivers of persons with dementia were provided. Other resources shared with the family included senior centers, adult day care services, in-home care, and the Medication Therapy Management Program (MTM). In specific, the MTM provides a comprehensive review of medications and an action plan to improve the overall health with the best usage of taking and managing medications (11). When implemented with people with Parkinson's disease, the MTM helped with not only medicine-related problems but also adherence to the treatment (12). Morgan addressed concerns about medicines that help her cognitive functioning, side effects, and possible interactions between all medications she was taking. The counselor referred her to this program, so that she can obtain accurate information from a pharmacist and comply with medication regimens (2).

Furthermore, Cruz-Oliver et al (13) suggested that visual information is efficient to convey complex medical and emotional situations. The first two counseling sessions were held in-person. As COVID-19 cases increased due to the delta variant spreading rapidly, sessions were virtually arranged. It was observed that virtual sessions were more efficient when sharing information about the disease and resources than sharing in-person. By using a teleconferencing platform, the counselor was able to demonstrate how to navigate the Medicare.gov website to find and compare healthcare providers and long-term care facilities as well as long-term care insurance websites. Also, visual aids were used to show infographics and images of a healthy brain compared to a brain affected by Alzheimer's disease assisting the verbal explanation of the impact and progression of the disease. To support clients' understanding of information given about the diagnosis, both written and visual information should be utilized in practice (4).

Examining Family Dynamics

Dementia can impact the relationships within the family. Therefore, family members' active involvement was required to understand family dynamics and examine the structure of the family. When Morgan's daughter took initiative on various discussions with other family members, Patrick felt left out and started having conflicts with her. As each family member was at a different pace of accepting Morgan's diagnosis, communication issues and additional stress arose. As family communication is considered a critical component in dementia care (14), counseling focused heavily on ways to improve communication among family members. During the sessions, the family was encouraged to have an open dialog about care preferences and care planning.

As Mitrani et al (3) suggested, the quality of family environments (eg, closeness and levels of conflict resolution) affects not only the stress of people living with dementia but also the emotional functioning of the caregivers. Therefore, the counselor focused on varying needs of the family members to maximize caregiver support over time. For example, Patrick struggled with accepting changing roles and relationships with Morgan. The counselor recognized

challenges he experienced (eg, taking over household finances) and helped him manage his stress and improve the ability to balance his own needs and Morgan's care needs.

Engaging in Research

Morgan and her daughter demonstrated their desire to be part of an effort to advance dementia and caregiving research. TrialMatch by Alzheimer's Association was introduced during a session as it connects people with dementia and their family caregivers to clinical trials. Recruiting participants, especially people in the early stage of dementia, for dementia research comes with many barriers. These barriers include people's lack of awareness of research opportunities (15) and that many potential participants are already in the late stages and cannot provide consent (16). Efforts to reduce the barriers through counseling are important as research shows that research participation can help increase access to healthcare as well as social contact (17).

Conclusions

This case report presented the process and benefits of counseling for those affected by dementia, using psychoeducation and family systems therapy. However, it should be noted that this case report is based on the authors' observations and discussions. While many counselors are equipped to provide therapy to alleviate stress and depression of individuals, it is important to foster and train counselors who are specialized in dementia in order to assist people with dementia and their family caregivers. Counselors can utilize methods from family systems therapy to help family members better cope with their changing roles in caring for their loved one with dementia and reduce inner-family conflict. With an understanding of the disease and dementia caregiving, counselors will be able to provide comprehensive care support, including delivering knowledge of the disease and resources to meet any unmet needs during the caregiving trajectory.

Ethical Approval

Ethical approval is not applicable for this article.

Statement of Human-Animal Rights

This article is a case report and does not contain any studies with human or animal subjects.

Statement of Informed Consent

Written informed consent was obtained from the patient for their anonymized information to be published in this article.


Declaration of Conflicting Interests

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ORCID iD

Kathy Lee  <https://orcid.org/0000-0001-9603-1685>

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