

Building a Bridge (between clinical and community care): Post-diagnosis support for persons with dementia and their families

Grant Number: 1R21AG056716-01A1

National Clinical Trial (NCT) Identified Number: NCT03932812

Principal Investigator: Sato Ashida

Sponsor: University of Iowa College of Public Health

Funded by: National Institute on Aging (NIA)

Revised Analytic Plan

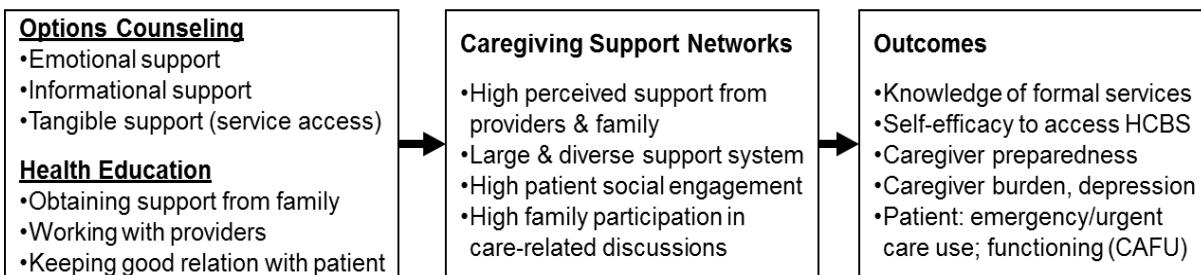
January 2022

Building a Bridge Data Analyses Plan

Overview of the Intervention. Building a Bridge: a post-diagnosis support of persons with dementia and their family aims to assist community dwelling individuals newly diagnosed with dementia and their families to prepare them for community-based care and connect them to the services provided by the local Area Agency on Aging. The intervention consists of two components, Options Counseling (OC) and Health Education (HE) – the OC-HE intervention. Families receive standard OC services provided through the Iowa's Area Agencies on Aging that include a family assessment, counseling and provision of emotional support, access to community resources and supports, and development of independent-living plans (family action plans). The HE component involves the provision of post-diagnosis education using the educational modules specifically developed for this project to address the needs of families who recently received the diagnosis. The intervention contains 8 modules to support successful role transitions for patients and family: overview of dementia (e.g., symptoms, stages, management, things to consider after diagnosis), anticipating changes and challenges, social relationships and daily life, interacting with providers, addressing future needs, dementia and driving, elder mistreatment, and pandemic-related challenges. The module on social relationships and interactions focus on enhancing social support through the discussion of strategies to elicit positive support from network members.

Interventions are ongoing and flexible to meet the needs of the individual family. Following the standard OC protocol, the family receives an initial telephone intervention (previously in-person home visit, but occurred over the phone due to the pandemic) by the interventionist. During the initial call, the OC uses assessment tool to identify caregiver/family needs and develop family action plans to connect families directly to services and programs available in the area. The interventionist also conducts an assessment to determine educational needs, then conducts 2 additional monthly follow-up calls to adjust the care plans and to provide educational components appropriate at each point (3-month intervention). This program, thus, creates direct links between the medical clinics, HCBS, and family. The OC tailors the information provision to meet the needs of those receiving it by providing additional information as the time progresses, allowing the recipients to identify their concerns at the moment and presenting materials to address expressed concerns. Participants receive all educational materials and a brief overview of contents at the end of the 3-months intervention period, including the topics that may not have been covered in great detail during the intervention calls. The Area Agency on Aging provides continued support to individuals who need their services after the completion of the intervention.

Mechanisms of Influence. The social network framework highlights the importance of enhancing network functions (e.g., social support) on health outcomes. Strong social support networks have been shown to be important for the well-being of caregivers and care recipients, and their ability to remain in the community. The intervention provides families 1) tangible, informational, and emotional support, 2) guidance on building strong support systems and effective communication, and 3) access service linking families directly to community-based resources. Through these activities, we intend to strengthen families' social networks to facilitate successful community living. In our prior study, families considered formal providers as important members of their caregiving support systems, suggesting the important role Area Agency on Aging staff can play in this mechanism. In this study, we are systematically examining the compositional and functional characteristics of social networks, that are theorized to influence patient and family outcomes. We will assess the mechanisms of influence using the social network measures specifically developed for dementia caregiving studies that assess social interactions specific to caregiving in addition to general support. Understanding the mechanisms through which intervention improves outcomes will provide a framework to optimize support for patients and their families across all stages of the illness.



Revised Data Analysis Plan

Network composition: Network members are enumerated based on participation in caregiving activities and provision of support to caregivers at baseline. In 3- and 6-month assessments, participants indicate changes in their networks (e.g., indicate those who are no longer part of support network, add new support providers). We will develop network composition measures including network size and proportion/number of family, non-family/friends, professional providers, live locally, gender, age groups (e.g., same/older/younger generations).

Perceived support: At each assessment, the participants report their relationships with each network member (e.g., who provides emotional support? Who helps you provide direct care? Who participates in discussions to make care decisions) to assess network functions. Levels of support can be determined by taking an average support levels among family, non-family, professionals, for each type of support (e.g., emotional, informational, instrumental, direct care, care decision making).

Social engagement: Participants identify network members with whom they engage in social activities to assess how the network functions as a context for social engagement.

At the patient level, generalized linear models (GLM) with an appropriate link function (e.g., the identical link for continuous outcomes, the logit for dichotomous outcome, and the log link for count outcomes) will be used to assess associations between the caregiver and patient outcomes and network composition and network functions. In particular, a set of the composition measures will be considered as independent variables to each outcome in a GLM. Similarly, a set of network functions (e.g., change between baseline and 3-month) will be included to assess the association with each outcome at 6-month in a GLM.

Follow-up analyses

Once we identify network functions that are important for the caregiver and patient outcomes (e.g., emotional support, provision of direct care support) are identified in the main analyses, we will be able to conduct dyad-level analyses to identify the whole network characteristics (e.g., network size, homogeneity), network member characteristics (e.g., gender, relationships, live locally), as well as relationship characteristics (e.g., presence of trust, duration of relationship) that may contribute to such positive network functions.

At the dyadic-level, a logistic regression model will be fitted for each outcome (e.g., presence of emotional support, provision of direct care support) using generalized estimating equations with the exchangeable correlation structure to account for the clustering of the network members within the respondents' networks. Both respondent-level (e.g., gender, relationship to care recipient) and network member-level covariates (e.g., family member of the care recipient, age, whether living locally) will be considered in these models. To assess the impact of changes in network functions, differences between baseline and 3-month network functions (e.g., change in support provision) will be used as independent variables to the outcomes at 6-months.