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The Alzheimer's Association Dementia Care Coordination Program: A Process Evaluation

Executive Summary

Prepared for the Massachusetts/New Hampshire (MA/NH) Chapter of the Alzheimer's Association

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Massachusetts/New Hampshire Chapter

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EXECUTIVE SUMMARY

Introduction

The Massachusetts/New Hampshire (MA/NH) Chapter of the Alzheimer's Association has long sought ways to systematically increase the number of families who utilize its services and support. According to the Alzheimer's Association's *2015 Alzheimer's Disease Facts and Figures*, there are 142,000 individuals living with Alzheimer's disease in Massachusetts and New Hampshire, and the Alzheimer's Association estimates that less than 30% of those individuals and their caregivers take advantage of its programs (Alzheimer's Association, 2015). The MA/NH Chapter recognized that one major barrier to accessing services is a model that relies on families taking the initiative to seek out assistance.

In 2005, The MA/NH Chapter of the Alzheimer's Association initiated the Health Liaison Program. Rather than relying on affected persons to reach out to the Chapter, the Health Liaison Program sought to improve chapter service utilization by encouraging health care providers to make direct referrals for families affected by Alzheimer's disease and related dementias (ADRD). After many years of operating the Health Liaison Program with existing staff, the Alzheimer's Association MA/NH Chapter decided to pursue funding to expand the Health Liaison Program into the more formal Dementia Care Coordination (DCC) program.

This study reports on the Dementia Care Coordination (DCC) Program. In 2013, with support from a non-profit health insurer, Tufts Health Plan (THP) and a private funder, the Eisenberg Family Trust, the development and implementation of the DCC Program became possible. Under the DCC Program, dedicated care consultants connect directly with persons with ADRDs and their families who are referred to the Chapter by health care providers. Once connected, the care consultant is able to provide disease-specific education, symptom management strategies, emotional support, and referrals to community resources and encourage the caregiver to utilize other Alzheimer's Association services including support groups, education programs, and advocacy opportunities. Consultants collaborate with other staff members and volunteers to provide ongoing information and support to families. Moreover, consultants provide written feedback to health care providers and nurse case managers on client needs and recommendations to meet those needs.

Connecting families affected by ADRD with the services and support of the Alzheimer's Association has important benefits for both the caregiver and

affected person. Integrating primary care with caregiver support will likely improve the health status and quality of life for the person with ARDA and family caregivers. Mittleman et al. (2006) has demonstrated that such support and education delays institutionalization and improves physical and emotional health outcomes for the caregiver. Unfortunately, many caregivers delay seeking any kind of assistance. Richardson (2012) reporting on a 2012 study by the Alzheimer Society of Canada, stated that 44% of caregivers for people with ADRD waited a year or more, after the first signs of dementia, to seek any kind of support.

The overall finding of this study is that the DCC program is highly successful and has engendered high levels of satisfaction by participants and multiple stakeholders. The DCC program represents an important element in a comprehensive integrated approach to patient care. Our analysis has also led us to make recommendations on how this important program can be improved, with the hope that it can be expanded and replicated.

How DCC Works

In the DCC Program reported on here, referrals were generated from two different streams – health care providers in the community and nurse case managers from THP. Two dedicated care consultants were hired to respond to referrals from each stream. Due to the nature and needs of these two referral systems, some key differences are important to note.

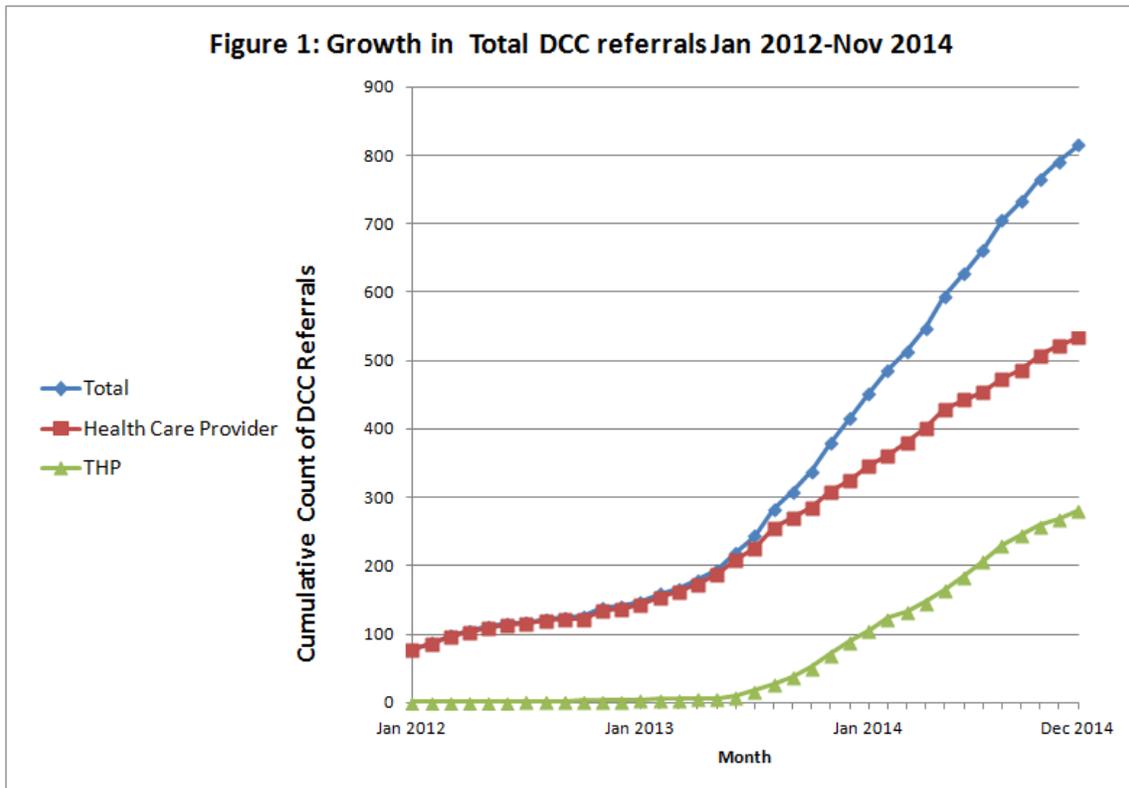
Referrals from health care providers are handled by a care consultant whose position was funded by a grant from the Eisenberg Family Trust. The referral base was initially health care providers affiliated with the original Health Liaison Program -- primarily physicians from three major medical institutions, Beth Israel Deaconess Hospital, Veterans Administration, and Boston Medical Center – but has since expanded to other health care providers. The grant from the Eisenberg Family Trust also funded a multi-year research study about the impact of DCC led by Dr. Andrew Budson at the VA Boston Health Care System and the Boston University School of Medicine, Alzheimer’s Disease Center. That study is ongoing at the time of this report.

Referrals from THP are handled by a full-time care consultant employed by THP but based at the MA/NH Chapter of the Alzheimer’s Association three days a week. This arrangement began in 2012. Initially, referrals were limited to nurse case managers in the Tufts Medicare Preferred Program, but grew to include nurse case managers in other Tufts insurance products. This care consultation supplements existing Tufts case management for people with complex needs. Its goal is to enable patients and their caregivers to better manage ADRD, hopefully

resulting in fewer negative health outcomes and higher satisfaction among plan members and their families.

Figure 1 contains a graph of the cumulative unduplicated counts of new referrals made to both arms of the DCC Program from January 2012 through November 2014 based on data from the Association's Helpline database. These data understate the actual care consultant DCC referral monthly workloads for several reasons. First, as unduplicated counts of individuals, they do not reflect multiple episodes of DCC referrals that can be made for the same individual when new issues arise. Second, data for eight referrals were omitted since we could not distinguish whether or not they were a THP referral. Third, and perhaps most important, the data only include those referrals for which full or partial caregiver's contact information (mail or e-mail) and referral date were entered into the Association's Helpline database. As a consequence of this reporting requirement, the degree of undercounting may be greater for THP referrals since we were informed that many THP referrals are not recorded in the Helpline database. Monthly counts of DCC referral episodes from care consultant workload data suggest that monthly counts of referrals for episodes of care consultation from both arms are nearly double the unduplicated counts of individual caregivers referred based on the Helpline database.

Despite the limitations of the Helpline data source, the graph in Figure 1 clearly shows that since 2013 the program has seen tremendous growth in the number of referrals received from both THP nurse case managers and from health care providers. In January 2013, the total DCC referrals numbered only 148. Twenty-two months later in November 2014, however, the Helpline data show that unduplicated counts of total referrals in both arms of the program increased to 815. Whereas health care provider referrals to DCC averaged less than six per month in 2012, average monthly referrals increased to about 17 in both 2013 and 2014. Despite the probable greater undercounting of individuals referred to DCC by THP, nevertheless the Helpline data still show that THP referrals have also rapidly increased, particularly in 2014. The THP average monthly rate of referrals to DCC of about 8.5 per month in 2013 nearly doubled to 15.9 referrals per month in the first 11 months of 2014.



This study reports on a process evaluation of the DCC Program. Components of the process evaluation included defining the structure, process, and expectations for the DCC Program among the key stakeholders, including staff at the Alzheimer's Association MA/NH Chapter, THP, and health care providers through key informant interviews; exploring outcomes and satisfaction with DCC through focus groups with Tufts nurse case managers and electronic surveys of referring health care providers, and through a mailed survey to caregiver participants in DCC. The report ends with suggested recommendations for improvement and replication both within the Alzheimer's Association MA/NH Chapter and beyond.

Methods

A process evaluation of the DCC program was conducted between June 2014 and May 2015 using a mixed-methods approach. There were 14 key informant interviews conducted with key staff members from the Alzheimer's MA/NH Chapter, staff members and administrators from THP, and referring health care providers. Two focus groups were conducted. The first involved six THP Case Managers from the Tufts Medicare Preferred plan. Seven more THP Case Managers participated in a second focus group, representing a variety of product

lines. Two surveys were conducted. One was an electronic survey of referring health care providers. The other was a mail survey to family caregivers participating in the DCC program. Lastly, descriptive analyses of contact data between DCC care consultants and caregivers, provide a snapshot of DCC care episodes from April 2009 through November 2014.

Results

Key Informant Interviews and Focus Groups

An analysis of key informant interviews and focus groups led to the development of a conceptual model that illustrates shared assumptions about how the program works and its critical components. According to the model, families should be directly referred by their health care provider to the Alzheimer's Association. Ideally, soon after diagnosis, the person with ADRD and their caregivers should be linked with specialized resources. The dedicated care consultants in the DCC Program function as the critical link to specialized resources. Under the model, the care consultant provides the caregiver with information and/or resources that enable him or her to ensure that the person with ADRD receives the necessary care and support. The care consultant also communicates her recommendations to the referring health care provider or THP nurse case manager for improved coordination of care for the person with ADRD.

Several major themes regarding the DCC Program's realization of this conceptual model emerged:

Early referral – The conceptual model for the DCC Program ideally has families referred to the DCC Program soon after diagnosis and/or in the early stages of the disease when the potential for support and services throughout the course of the disease is greatest. However, data collected in key informant interviews and focus groups indicate that the majority of referrals to the DCC Program are not recent diagnoses and are for people in later stages. Key informants and focus group participants provided insights for reasons why referrals to the DCC Program tend to be for individuals in later stages of the disease:

- Many of the referring health care providers are specialists, not the primary care physicians who likely are the first points of contact where patient concern is raised. Specialists are often consulted when challenging behaviors emerge later in the disease process.
- The structure of the THP referral mechanism makes it likely that the person with ADRD will be in the later stages of the disease when referred.

Nurse case managers serve as gatekeepers to the DCC consultant; eligibility for case management is determined by a predictive model that is largely focused on complex chronic conditions and cost containment. Consequently, most referrals from THP nurse case managers are individuals with co-morbidities that include ADRDs. Many more THP members, who are at an earlier point in the disease process but are not eligible for nurse case management, could benefit from the program but are not likely referred to it.

- The DCC Program's mechanisms for early referral could be improved.

Coordination of care– In the conceptual model for the DCC Program, a key role of the care consultant is to facilitate the flow of information among caregivers, referring health care providers, and THP nurse case managers. This communication is key for the coordination of best care possible for the person with ADRD. In the coordination of care, the consultant plays an important role in educating all parties about dementia, through both direct consultations and targeted training activities. Overall, the data clearly showed that investment in communication and data management systems has considerable potential to increase user satisfaction among referral sources and efficiency more generally for the DCC Program.

One of the key issues in the practical operation of the DCC Program and this research study was the recording, tracking, and analysis of information. During the time of the study, the national Alzheimer's Association was shifting all chapters to a single customer relationship management system, which presented challenges to the MA/NH Chapter in tracking and coordinating information for its DCC Program. This shift highlighted issues about the Chapter's former database and information management systems and affected the ability to obtain data for the study and affected use of the existing data for this study. It was clear that case notes could be kept and data gathered more consistently. If the Chapter wants to move toward a more data-dependent approach to program management, it will need to maximize the capability of the new customer relationship management system to record, track, and analyze information.

In terms of the THP consultant, the dual data systems operated by the Chapter and THP caused problems in terms of the linkage between the Chapter and THP case managers. These problems were exacerbated by THP's need to comply, not only with the data protection requirements imposed by the 1996 Health Insurance Portability and Accountability Act (HIPAA), but also with the more stringent security requirements imposed by its contract with the U.S. Department of Defense. This meant that the Chapter could not access THP patient data, nor

align its information systems easily with THP. This caused inefficiencies for the THP care consultant, who had to duplicate documentation of information. In addition, the care consultant could only access case management notes for the THP case managers, but not for the external case managers.

Both consultants experienced issues in communicating with physicians, who work with different electronic medical record systems that have varying degrees of security and have differing preferences regarding their preferred mechanisms for communications – either by fax, phone, or email. The health care provider survey revealed this finding in more detail and highlighted the need to identify reliable, user-friendly, HIPAA-compliant mechanisms for communication with health care providers. Specifically, the data show that only about one-third of health care professionals prefer to use the recommended referral method (i.e., use the DCC referral form and transmit it via secure fax). Roughly another third of respondents report using the DCC referral form but send it to the DCC consultant via e-mail rather than secure fax. A quarter of respondents prefer to send a personal note or patient case notes via e-mail to the DCC consultant rather than use the DCC referral form.

Workflow and demand management –With care consultants reporting that their caseloads routinely exceeded the targets set per consultant per month, outreach efforts were limited. Care consultants confronted competing priorities in both responding to client needs and providing outreach and education. There was concern among Chapter staff members and THP nurse case managers, in particular, that successful outreach efforts would outstrip the capacity of the care consultants. Demanding workloads and limited capacity for growth also reduced motivation for addressing systematic ways to identify clients at earlier stages of the disease, one of the overall goals of the Dementia Care Coordination Program.

One way to manage the workload was to utilize dedicated volunteers, trained in the 24/7 Helpline and care consultation, to support the DCC care consultants. Due to the higher level of expertise required for this function, the Chapter decided to pay one Helpline volunteer on a per diem basis to follow up on existing referrals and to free care consultants to respond to new referrals. Although this solution worked, it is unclear if it is sustainable. Clearly, there is a need to identify priorities and develop strategies to manage long-term demand.

A further conclusion regarding the care consultants' role is to appreciate that the education component could be delivered by other staff. Clearly, the education program served both to publicize the program and to provide people with information about ADRDs. However, such outreach need not be performed by

care consultants, who have more than enough demand for their services. One way to lighten their load would be to separate out such activities. ***Value added for physicians and case managers*** –The DCC Program supplements the work of referring health care providers and THP nurse case managers in two ways: by providing expertise that health care providers or nurse case managers lack or do not have time to communicate, and by providing referrals and supports that are not otherwise available. Among THP nurse case managers, there was wide agreement that the care consultant does not duplicate their existing work, and, overall, reduced their workload. The referring health care providers also agreed that the DCC Program augments existing resources, and is an overall net gain. The referring health care providers interviewed noted that they lacked the capabilities of the DCC Program within their own practices and implied that they were unlikely to add these resources due to the associated costs.

For both referring health care providers and THP nurse case managers, there are clearly some ways that the relationship imposes burden through the additional paperwork required and the staff time associated with communication and coordination. However, overall they agreed it was a clear net benefit.

Health Care Providers' Survey

Health care providers play a critical role in the DCC Program model. Apart from THP nurse case managers, these health care providers are the primary entry points into the DCC Program. For the DCC Program to be successful over the long term, health care providers must be aware of the program, believe that it benefits patients and/or caregivers, and be satisfied with the operational processes involved in the program. To obtain a broader range of health care provider perspectives on the DCC program, we sent an Internet survey to 25 referring health care providers and asked them to share the survey with others in their practices.

Fifteen health care providers responded to the survey and were generally very satisfied with the DCC Program, believing that it helps patients and caregivers to better manage the challenges of dementia. Health care providers generally discuss care consultants' recommendations with their patients, but they do not know very much about whether patients follow up on them. Although health care providers do not find the referral form difficult to use, they do find the process of completing the form by hand and submitting it on a secure fax burdensome, given their time constraints. Several health care providers suggested that a simpler electronic referral process would be desirable. Finally, there was widespread consensus among providers that some type of brochure would be helpful for explaining the DCC Program to patients and caregivers.

Caregiver Survey

Ultimately, the DCC Program aims to benefit caregivers and care recipients. To assess caregivers' experiences with the program, they were mailed a survey to learn about their experiences, satisfaction levels, and recommendations for program improvement, as well as other Chapter connections they may have made. The mail survey was sent in February 2015 to 635 caregivers whose mailing addresses were known to the Chapter, along with a return postage-paid envelope. There were 136 caregivers who responded to the survey (a response rate of 21%). Relative to non-respondents, those who returned the surveys tended to have had greater contact with the care consultant over a longer period of time, but there were no significant differences in referral dates to DCC, first contact dates with DCC, and last contact dates. Relative to the Massachusetts older adult population, respondents were more likely to be highly educated women and less likely to be Hispanic.

The Dementia Care Coordination Program strives to connect families with the broad range of services provided by the MA/NH Chapter of the Alzheimer's Association and to be an ongoing source of support and information throughout the disease process. Overall, respondents overwhelmingly expressed great satisfaction with the support and services received. When asked in what ways the DCC Program was helpful to them, more than half of the caregivers reported that it offered support and reassurance (81%), increased their knowledge and understanding of Alzheimer's disease (52%), and helped them to better cope with caregiving stress (51%). About half, 49%, indicated that the DCC Program was helpful in connecting them to needed community resources. Most notably, some respondents commented that they now had the language to communicate with health care providers, the legal system, nursing homes and assisted living facilities, and with other family members and friends. They appreciated being able to connect with the MA/NH Chapter of the Alzheimer's Association as needs arose throughout the disease process. In addition, close to 60% of the caregivers surveyed reported that they participated in at least one chapter service or educational program beyond the DCC program. The most frequently mentioned areas of participation were support groups, education programs, and registration in the Medic Alert® + Safe Return®+wanderers alert program.

Conclusions and Recommendations

The overall finding from this study is that the DCC Program is highly successful in terms of the level of satisfaction expressed by stakeholders in the program: administrators, health care providers, nurse case managers, Chapter staff members, and – most importantly – those living with the consequences of the disease and their caregivers.

By providing critical supports to ensure the appropriate management of ADRDs, the DCC Program represents an important element in a comprehensive integrated approach to patient care. Central to the success of many coordinated care initiatives is the involvement of community-based organizations, which not only may offer expertise outside of the medical system, but also may facilitate access to a broad network of resources. The DCC Program is an example of such a mechanism for linking the medical system with community resources that directly support caregivers and promote quality care and positive patient outcomes— another important policy priority. In state and federal public policy initiatives, the Alzheimer’s Association is evaluating how to expand coordination of care for people with ADRD. Furthermore, the Alzheimer’s Association is looking at the DCC Program to evaluate whether this can be replicated in other states.

The partnership between THP and the Chapter is especially significant in that THP has been willing to invest financially in the DCC Program. This investment reflects not only a growing awareness of the need to serve people with ADRD; it also reflects a shift in perspective about the appropriate model of care for this population and its caregivers. The partnership demonstrates a recognition of the critical role that supportive services, such as those offered by the Alzheimer’s Association, can play in the medical management of ADRDs.

Given the critical role of such support services, linkages with medical systems can be a potential source of financing for often-underfunded community partners. Of course, to warrant such funding, organizations need to be able to demonstrate concrete results; hence, the emphasis in our recommendations on the need for improved data collection, accountability, and efficiency regarding DCC Program performance.

Thus, in conclusion we recommend that the Chapter

- Identify systems to draw the person with ADRD into the DCC program at earlier stages in disease progression and sooner post diagnosis at any stage.
 - The Tufts DCC program can likely do this through leveraging data resources available through the health plan.

- Accessing other potential participants is more challenging: it will depend on developing strategies to draw in primary care practices.
- Develop mechanisms to improve direct, HIPAA-compliant communication with physicians.
- Invest in better branding via the Chapter's website and clear and accessible brochures. This can both support and advertise the DCC program.
- Invest in a broader educational campaign, targeting health care providers, about the importance of early diagnosis and referral to the MA/NH Chapter of the Alzheimer's Association.
- Explore mechanisms for systematically reaching out to a less educated population.
- Increase opportunities to connect DCC participants with other Chapter services and support.
- Develop systems for accountability and quality control.
- Obtain quantitative data showing the value of the DCC, as part of an overall strategy to generate a payment stream to support DCC activities and encourage others to replicate the model.

As the MA/NH Chapter of the Alzheimer's Association considers these recommendations as it plans for the next phases of the DCC program, we have no doubt that it will emerge as a model that could be replicated across the Chapter network.