

Executive Summary: Massachusetts' Home Care Programs and Reasons for Discharge into Nursing Homes^{1, 2, 3}

Prepared by:
Cathy M. Wong, M.A.
Nina M. Silverstein, Ph.D.
Gerontology Institute,
University of Massachusetts Boston

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Mass Home Care



EXECUTIVE SUMMARY

INTRODUCTION

Home and community-based services (HCBS) are a range of long-term care services intended to enable older adults and persons with disabilities to “age in place” in their own homes and communities. Previous studies well document that older adults prefer receiving HCBS rather than institutional care at a nursing home (e.g., Walker, 2010; Fox-Grage, Coleman, & Freiman, 2006). One study concluded that 84 percent of older Americans, aged 50 years and older, want to remain in their homes for as long as possible (AARP, 2005). Medicaid is a major source of funding for long term care. Currently, a large proportion of Medicaid funds in most states has been spent on institutional care (National Conference of State Legislatures & AARP, 2009), and older adults and their families have relied on nursing homes to be the provider of long-term care (Miller, Allen, & Mor, 2009).

In 2006, the national average of the proportion of Medicaid long-term care spending for disabled older adults and persons with disabilities going to institutional care was 75 percent, while 25 percent was directed towards HCBS (Kassner et al., 2008). Similar to the national average, the proportion of Medicaid long-term care spending for institutional care in 2006 was greater than the proportion for HCBS in Massachusetts with 78 percent of Medicaid long-term care spending directed towards institutional care, and 22 percent going to HCBS (Kassner et al., 2008). Moreover, in 2007, Massachusetts had nearly 25 percent greater rate of nursing home utilization than the national average (Wallack et al., 2010). As of 2008, according to the Massachusetts State Profile Tool, approximately 60 percent of MassHealth (Massachusetts’ state Medicaid program) long-term care spending is spent on nursing facilities.

Massachusetts’ Home Care Program Services

This report is focused on and limited to three main programs in Massachusetts that provide HCBS: Home Care Basic, Community Choices Program (Choices), and Enhanced Community Options Program (ECOP). These three home care programs are not the full complement of HCBS in the Commonwealth. MassHealth’s (Medicaid) role in HCBS is as a payer of services. The home care programs are administered by Aging Service Access Points (ASAPs) under contract with the Executive Office of Elder Affairs (EOEA). The EOEA is the State Unit on Aging. The EOEA provides home care services statewide holding contracts with 27 ASAPs throughout the Commonwealth. ASAPs are described as a single entry point for elders in the community, and services provided by ASAPs include care management, information and referral, nursing home pre- and post-admission screening, development of service plans, and monitoring of service plans.

The home care programs provide services to eligible elders who need assistance so they may continue to live independently in their homes and communities. An interdisciplinary team that consists of care managers and nurses from ASAPs conducts an assessment in the elder's home to determine eligibility for the programs. Care managers assess clients' needs and provide service plans that meet their needs, incorporating informal supports, other available resources, and utilizing the home care funded programs as part of the service plan. Individual services needs and a personalized service plan are developed with elders and their family members.

Research Objectives

This study provides a snapshot of clients enrolled in three home care programs by examining the sociodemographic characteristics, health status, and unmet needs assessed among clients at one point in time in 2010. Additional qualitative data are used to explore care managers' perspectives on the reasons home care clients in Massachusetts are discharged into institutional long-term care settings. The report concludes with recommendations to enhance the delivery of home care program services in Massachusetts.

METHODOLOGY

Three sources of data are used to address the research objectives of this study: qualitative data from in-person interviews with 17 care managers and one registered nurse in spring 2010; aggregate data provided by the Massachusetts Executive Office of Elder Affairs through their Comprehensive Data Set; and a sample of journal entry notes from care managers and nurses that were provided from one ASAP.

Care Managers' Perspectives

UMass Boston gerontology students enrolled in a spring 2010 Aging and Social Policy seminar, in partial fulfillment of the requirements of the undergraduate major in gerontology and Certificate in Gerontological Social Policy, conducted a research project titled, *Discharge from Home and Community-Based Services to Nursing Homes in Massachusetts: Care Managers' Perspectives*. The research objective of the project was to explore care managers' perspectives on the reasons home care clients in Massachusetts are discharged into nursing homes.

After receiving approval from the Institutional Review Board (IRB) at UMass Boston, student researchers conducted in-person interviews with a convenience sample of care managers at eight ASAPs. A total of 17 care managers and one registered nurse were interviewed at their respective agencies. It should be noted that the registered nurse was interviewed due to the care management role she served at one ASAP that had few care managers to participate in the study. Care managers and the registered nurse were asked their perceptions about clients' barriers to remaining in the community that may lead to discharge into nursing homes. Herein, the data are presented for the total 18 care managers. The study prompted pursuing further data sources on examining the

home care programs in Massachusetts, and this current report provides the additional data beyond the student research.

Comprehensive Data Set

The Comprehensive Data Set (CDS) enabled an examination of the clients enrolled in three home care programs in Massachusetts (Home Care Basic, Choices, and ECOP). The data were provided in aggregate form by the Massachusetts Executive Office of Elder Affairs. The CDS is a comprehensive questionnaire used by care managers and registered nurses for assessments with clients enrolled in the home care programs. Care managers monitor clients' needs and their service plans by conducting reassessments. Reassessments are performed at home visits in the clients' homes. For the Home Care Basic program, reassessment is required no less than every six months or as often as necessary when circumstances for a client changes. For the Choices and ECOP programs, reassessment is required no less than every three months or when a change occurs.

The data were provided for March 2010 and allow for a relative comparison of home care clients during the same period of time that the student interviews with care managers occurred. Caution should be exercised in generalizing these findings as these were not matched comparisons. The authors' intent is to provide some insights that may generate further exploration. During that time, a total of 32,417 clients were enrolled in the Home Care Basic program, 5,221 clients were enrolled in Choices, and 4,563 clients were enrolled in ECOP, which yields a total of 42,201 home care clients. This current study's analysis is presented as percentages and examines clients by each of the home care programs, which allows for program-to-program comparisons within the CDS.

Care Manager Journal Notes

To further explore reasons for discharge from the home care programs into nursing homes, a sample of 150 journal entries were reviewed for 15 clients during the months of February, June, and July 2010. Care managers and nurses document field notes of their clients and it was expected that these journal notes would provide more detailed information on reasons why clients are being discharged from the home care programs. The journal notes were reviewed and analyzed by identifying frequent themes mentioned for termination.

RESULTS

Comprehensive Data Set

The CDS was used to present a snapshot of clients enrolled in the home care programs in March 2010. Overall, home care clients are predominantly older women (75.4%) who are widowed (47.6%) and live alone (62.3%). Hypertension was the most prevalent disease diagnosis among the clients, with 80.4% of Choices clients reported as having the health condition. Clients from Choices and ECOP were much frailer and had more disease diagnoses than clients from the Home Care Basic program.

Doctors and hospitals account for very few referrals for home care services, 2.5% and 9.4% respectively. Over a third, 37.6% of total home care clients were taking nine or more medications. Also, 64.3% of total home care clients reported experiencing unsteady gait. A large proportion of Choices and ECOP clients, 66.3% and 67.6% respectively, report having limits in going outdoors due to fear of falling.

Critical Unmet Needs

Critical unmet needs are defined in the home care regulations (651 CMR 3:00) as a client's inability to perform or have someone else available to assist with any one or more of the following: any activity of daily living (ADL), meal preparation, food shopping, transportation for medical treatments, respite care, and home health services. An identified critical unmet need is required for eligibility for service on initial assessment or else clients are not enrolled in the home care programs. Clients from Choices and ECOP have more critical unmet needs. Over half, 52% of Choices clients and 47.9% of ECOP clients were reported as having critical unmet needs. Assistance with any ADLs, meal preparation, food shopping were the major critical unmet needs reported among Choices and ECOP clients. Caution should be exercised in interpreting these data in that they reflect one point in time and were provided in aggregate form, therefore it cannot be determined if these are ongoing unmet needs or the initial unmet need that determines eligibility and then was reduced or met through services later delivered.

The CDS has information on clients making trade-offs in purchasing prescribed medications, sufficient home heat, necessary physician care, adequate food, or home care during the last month due to limited funds. Almost all of the total home care clients, 97.9%, were noted as having made trade-offs.

Informal Support

More than two thirds (67.8%) of elderly home care clients do not live with their caregivers. The majority of caregivers for home care clients are a child or child in-law. Among the total home care clients, only 11.7% of caregivers are spouses, consistent with the majority of total home care clients being widowed females. A small proportion, 3% of Home Care Basic clients, 2.6% of Choices clients, and 1.6% of ECOP clients were reported as not having a caregiver. Concerning advance directives and responsibility, over half, 55%, of home care clients were reported as not having a health care proxy; 72% do not have a power of attorney; and 85% do not have advance medical directives in place.

Reasons for Termination from Home Care Programs

For fiscal year 2010, the major reasons for discharge from home care programs aside from transfer between programs were due to death and nursing home placement. About 13% of Home Care Basic clients, 17% of Choices clients, and 20.6% of ECOP clients were terminated from the home care programs and placed into a nursing home. Based on the total cases examined, 14.5% of cases were termination due to nursing facility placement, or 3,627

elders. Regarding death, 13.9% of Home Care Basic clients, 17.3% of Choices clients, and 21.4% of ECOP clients had passed away.

Care Managers' Perspectives

Overall, the majority (72%) of the care managers stated that clients are maintained longer in the community today than in past years. While they thought that more supports are available in their communities today, there were some notable exceptions.

This study found that addressing the need for 24/7 care in the home, in the opinion of several care managers, could potentially prevent or delay nursing home placement. Care managers were asked what additional services are needed to maintain clients in their homes. From the 18 care managers interviewed, 14 reported that 24/7 supervision could potentially delay institutionalization. One care manager expressed, “... *personal care services and people who need general supervision. So that can fall under companions if you need 24-hour supervision then it's very unlikely you'll be able to get it from the state.*”

Another care manager stated, “*I think weekend services. It's easy to get services Monday through Friday. Weekends and night services, especially helping people get to bed. Overnight help to monitor clients.*”

The care managers also noted a lack of informal caregiver supports and safety concerns, such as wandering among clients with Alzheimer's disease. Lastly, the majority of care managers reported that lack of exercise and poor nutritional habits are risk factors for their clients

Care Manager Journal Notes

Consistent with care manager interviews, the journal notes reveal that the need for continuous 24-hour care is a reason for discharge to a nursing facility. Often the need for 24/7 support and supervision is combined with other factors, such as the intensity of care required (e.g., two person assist). Frequent reasons for discharge into nursing homes noted in the journal entries were: the need for 24/7 care, risk and history of falls, a lack of informal support at home, the need for respite and support for informal caregivers, reaching a maximum of assistance with ADLs and IADLs, and the severity and number of medical conditions that are challenging to manage in the home.

CONCLUSIONS AND RECOMMENDATIONS

This study provide a snapshot of clients currently served by the three home care programs and insights from care managers as to reasons for discharge for HCBS to nursing home settings. We conclude by highlighting some of the findings and offering some recommendations to enhance the delivery of HCBS in Massachusetts.

Medication Administration: As reported from the CDS data, over a third, 37.6%, of total home care clients were taking nine or more medications. Because

clients use multiple medications, and often have trouble keeping them straight or remembering to take their medications, improved services for medication management may be needed for clients. Future research might address concerns for polypharmacy and level of medications' compliance among home care clients. Programs might also explore enhancing assistance in the area of medications' management.

Evidence-Based Fall Prevention Programs: As reported from the CDS data, an estimated 64% of total home care clients were experiencing unsteady gait. A large proportion of Choices and ECOP clients, 66.3% and 67.6% respectively, were reported as having limits in going outdoors due to fear of falling. The care manager interviews also highlighted the need for increased fall prevention. Currently, interventions do exist on fall prevention. ASAPS are involved in the 'Matter of Balance' evidenced-based program. An assessment of the program and expansion if warranted should be considered due to the large proportion of home care clients experiencing unsteady gait and balance.

Improved Coordination with Medical Providers: As the CDS data indicate that doctors and hospitals account for very few referrals for home care services, 2.5% and 9.4% respectively, efforts should be explored to create better linkages with medical home providers and with hospital discharge staff. Improved communication may help reduce inappropriate or unnecessary admissions to hospitals and nursing facilities. Moreover, an estimated 52% of Choices clients and 41% of ECOP clients feel multiple periods of pain daily. Further, more than half of Choices clients, 56%, reported that the intensity of their pain disrupts performing usual activities. The home care programs currently do not provide services for pain management. Interventions in pain management should be available, as part of the chronic disease management program and better coordination with medical providers could address that need.

Risk Assessment: Safety was an important theme for the care managers interviewed. Safety of the client is seen differently by the client, the family, and the care manager. Tolerance for safety may also vary from client to client. Use of negotiated risk assessments with clients and family members might help to identify the risks, and clarify what the "safety" issues really are for all parties involved.

24/7 In-Home Supports: A major theme in the care manager interviews is the need for 24/7 care. Consumers who wish to remain at home need to have the ability to assemble care plans on short order, including coverage for overnight care and weekends. Community care plans need to be as straightforward to assemble as a nursing facility placement. This could include short-stay adult foster care placements, and special extended care response teams of homemakers and home health aides. Moreover, clients in home care could be maintained in the community if there were intermediate steps between care at home and care in a nursing facility. 24/7 supports can require combining housing

with services such as supportive housing sites, or a small group home facility for individuals unable to live alone.

Self-Managing Chronic Conditions: Some clients terminated from the home care program and transferred to a nursing home have multiple medical conditions---which alone may not require discharge from home care, but in combination create the sense of overwhelming need. As a preventive measure, programming to provide individual, in-home chronic condition self-management support may help clients manage their chronic conditions with better outcomes. Hypertension (64.8%), arthritis (53.8%), and diabetes (30.6%) were the most prevalent health conditions among total home care clients noted in the CDS data. There are chronic disease self-management programs in the home care system today, but additional development of programs and interventions for these conditions may be warranted.

Care Manager Discharge Training: Care managers do not have a direct role in the decision to discharge, the decision resides with the older adult and family members. In the qualitative interviews, care managers were asked how much input they typically have in the decision to discharge clients from HCBS to a nursing home. The majority of care managers reported that they have some input, while “*the decision is from the clients’ families.*” Care managers were asked about what factors are considered by their clients and families in the decision to discharge from home care programs into a nursing home. One care manager explained that safety concerns and a lack of informal support at home are considerations for nursing home placement. A special curriculum designed to help care managers approach the discharge process would be helpful to better understand how to work with family dynamics; how to assess their own professional and personal attitudes towards safety; and how to ensure that the consumer’s voice is given the weight it deserves.

Need for Additional Research: Additional study of terminations from home care should be conducted, focusing especially on service gaps identified in the journal notes. The journal entry notes provided insights into reasons for discharge among clients that may not have been captured from the CDS. Future studies focusing on service gaps could include a more comprehensive analysis using journal notes as well as interviewing clients and family members. In addition, future studies might be conducted in examining the role of the care manager, client, family members, and doctors in the decision making process. It is recommended that strategies be developed in working with healthcare providers (e.g., doctors, private physicians) and community-based providers to promote awareness of the availability and viability of community-based options.

A limitation of this study is the small sample of care managers who were interviewed for the applied research project. The nature of qualitative data is to use few subjects to collect in-depth data. Much was learned from these data. However, generalization is limited in that these care managers do not represent all care managers in the Commonwealth. Building on this current study, an electronic study of all care managers is planned for spring 2011. We look forward

to collecting additional insights on this issue. Another limitation is the missing cases from the CDS data. We learned that the data needs are time consuming for the care managers and not all data are fully entered. Still, the study provided relevant information on reasons for client discharge. EOEAs might revisit their reporting forms with the goal of minimizing missing data. It would be helpful to conduct additional studies on terminations from home and community-based care, focusing especially on service gaps identified in journal notes, and examining the role of the care manager, client, family members, and doctors in the decision making process. It is recommended that strategies be developed in working with healthcare providers (e.g., doctors, private physicians) and community-based providers to promote awareness of the availability and viability of community-based options. It is hoped that ASAPs, other elder services groups, and policy makers will use this report to develop additional responses to address the identified service gaps in community-based programming.