

Policy Options for Adopting Patient Navigation into Alzheimer's Care and Support with Annotated Bibliography of Key Studies

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This paper introduces the concept of patient navigation with brief background, lays out the case for its use in Alzheimer care and examines the policy possibilities for payment of patient navigation services for persons with Alzheimer's. The policy section has a special emphasis on what state government might do and provides current information on states approaches to credentialing.

This is followed by an annotated bibliography of key background literature on the patient navigator model and a list of additional sources.

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Alzheimer Patient Navigation Services: Policy Options

Introduction to patient navigation

In recent years, care coordination and patient advocacy have emerged as buzz words in the healthcare industry. Much hope lies in using both care coordination and patient advocacy to help close gaps and alleviate shortcomings in the healthcare system. Advocates contend that when a patient is involved in his care, and it is coordinated from a centralized point in the system, such as through health or medical home, improved patient outcomes and lower healthcare costs occur.

Central to the success of these models is a professional whose role is to coordinate the care—often this person is a nurse or a social worker, referred to as a care coordinator, care manager, patient navigator, patient advocate, or some similar title. In practice, each of these titles may correspond with slightly different job descriptions or even the same title may mean different things depending on the job setting or employer.

Despite the lack of uniform agreement on job descriptions or what the subtle differences are among titles, common characteristics of these positions include:

- Conducting an assessment of a patient's needs.
- Developing, implementing and updating a holistic patient plan of care and services.
- Advocating for the patient's rights as he moves through the healthcare continuum to eliminate barriers and provide access to the most appropriate services and supports.
- Educating the patient and his family and informal support network about the patient's health issues, the healthcare system, and any pertinent healthcare planning.

These professionals assist a variety of patient needs; their roles may be disease specific or focus on a variety of patients. Their average case loads may vary from as little as five patients to as many as 400 patients. Some of these professionals provide services over the phone and through electronic systems without ever meeting the care recipient, while other models emphasize face-to-face interaction. Indicative of its emerging role in the healthcare system, very little regulatory oversight exists, and no major third-party payer reimburses for these services.

This brief uses the term “patient navigator” and lays out the case for why patient navigators are a key element of providing optimal care and support for people with Alzheimer's. Adapted from the cancer community, the patient navigator model is a robust, person-centered hybrid model of care coordination and patient advocacy. The words patient navigator emphasize the most important elements of the service—focusing on the person with Alzheimer's and arranging the services and supports he requires based on his individual needs to ensure the person maintains quality of life and receives quality care.

Patient navigation: the cancer model

Although patient navigation is a popular, current topic, cancer patient navigation programs actually have existed since the 1990s. The Oncology Nursing Society, the Association of Oncology Social Work, and the National Association of Social Workers, define cancer care patient navigation as “individualized assistance offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from prediagnosis through all phases of the cancer experience.”¹ Through navigation, these programs seek to achieve: “Improved early cancer detection; Increased adherence to cancer screenings and treatment; Decreased health care costs; Improved survival rates; Client ease in communicating with the health care professionals and assistance in accessing care and resources; Better utilization and matching of correct medical resources for patients.”² These broad descriptions, coupled with the fact that at its core patient navigation must respond to and support the specific needs of the individual, mean that the operation of cancer patient navigator programs vary.

Costs associated with operating a navigator program vary based on the scope and intensity of the program. According to C-Change, a prominent cancer advocacy organization, cancer navigation programs typically include costs for: personnel, training, supervision, professional meetings or continuing education, office space and utilities, supplies, telephones including mobile phones, computers and networking needs, information technology support, transportation, travel/mileage reimbursement, auto insurance protection, marketing and outreach, sustainability and possible replacement costs from loss such as turnover of well- trained staff to other positions.³ Due to the complexity of Alzheimer care, an Alzheimer patient navigator program likely would include similar costs.

¹ Oncology Nursing Society, the Association of Oncology Social Work, and the National Association of Social Workers Joint Position on the Role of Oncology Nursing and Oncology Social Work in Patient Navigation, Oncology Nursing Society, <http://www.ons.org/Publications/Positions/Navigation>

² Frequently Asked Questions (FAQs) for Cancer Patient Navigation (CPN) Programs, C-Change, www.cancerpatientnavigation.org/docs/FAQ.doc

³ Frequently Asked Questions (FAQs) for Cancer Patient Navigation (CPN) Programs, C-Change, www.cancerpatientnavigation.org/docs/FAQ.doc

Patient navigation: the case for Alzheimer's disease

Alzheimer's is a debilitating disease with no cure that presents spiraling cultural, economic, emotional, social and healthcare challenges. In 2012, the federal Medicare and Medicaid programs expended an estimated \$140,000,000,000 to care for patients with Alzheimer's disease and this figure will grow to \$850,000,000,000 by 2050 as the number of Americans with Alzheimer's who are age 65 and older grows from 5.4 million to at least 11 million.⁴ Additionally in 2011, 15,248,740 unpaid caregivers provided \$210,467,017,597 worth of care to people with Alzheimer's and dementia nationwide.⁵

Besides the overall cost of Alzheimer care, the healthcare system has grown increasingly difficult for any consumer to navigate, let alone someone with cognitive issues. Healthcare systems also have shifted in recent years to increase access to home and community-based services. Overall these changes are for the better, but also mean that a person with Alzheimer's now may have more individuals and services involved in their care and a greater chance of picking a care option that is not the most appropriate for their needs.

As the healthcare system increases its focus on care coordination, individuals with Alzheimer's disease should rise to the top of the list of disease populations most appropriate for patient navigation services. However, due to the unique needs of people with Alzheimer's, a cookie cutter model of patient navigation will not succeed. To make the greatest inroads in bending the cost curve of the disease and maximizing quality of life for the person with the disease and their family, similar to the cancer-specific model, an Alzheimer-specific model of patient navigation is necessary. Programs must be crafted toward how a person with Alzheimer's and their family move through the care continuum and maintain the flexibility to respond to changing needs.

Cancer patient navigators are credited with helping patients get screening and diagnostic tests to help improve early detection and treatment, while also decreasing mortality. With no cure for Alzheimer's, an Alzheimer patient navigator's role is slightly different, and instead, must shepherd the person with Alzheimer's and their family through the different stages of the disease ensuring they have access to the care and services they need. Receiving a timely diagnosis remains a challenge for Alzheimer's, and once received, a diagnosis is startling news. Ideally, if a patient navigator could enter the process as soon as the diagnosis is made, a person with Alzheimer's could begin to receive the assistance they need sooner.

⁴ 2012 Alzheimer's Disease Facts and Figures, Alzheimer's Association, http://www.alz.org/downloads/facts_figures_2012.pdf

⁵ 2012 Alzheimer's Disease Facts and Figures, Alzheimer's Association, http://www.alz.org/downloads/facts_figures_2012.pdf

The most effective Alzheimer patient navigators will be well-trained Alzheimer specialists with intensive and equal understandings of the clinical and human components of Alzheimer's and its impact on both the person and their family. Navigators also must possess a strong understanding of the health care system and the available services. Unlike some other forms of care coordination, an Alzheimer patient navigator would provide a high percentage of their services in-person. Although patient navigator models utilizing lay coordinators do exist, due to the complexity of care issues surrounding Alzheimer's and also in the interest of presenting the best possible case for reimbursement, a professional navigator model utilizing a nurse, social worker, or psychologist is most appropriate. A variety of entities could employ Alzheimer patient navigators, including healthcare systems, geriatricians' practices, and nonprofits such as the Alzheimer's Association. Additionally, many patient navigators currently are self-employed individuals that market themselves to families who pay directly for their services.

Patient navigation demands that services are tailored to the patient's needs and the specific barriers they face; key roles for an Alzheimer's patient navigator may include:

- assisting with locating and accessing clinical care
- accessing long-term care services such as nursing and assisted living care, in-home care, and adult day care
- connecting with social services such as support groups, transportation, and respite care
- providing health education on disease progression and treatment options
- maximizing insurance benefits and ensuring claims are paid
- working with family members to access support services and understand the disease
- providing guidance in end-of-life legal, financial and medical decision making

Providing this level of support will particularly help certain niche populations. For example, the approximately 800,000 Americans with Alzheimer's (one in 7) who live alone.⁶ Studies have found that a person with dementia who lives alone enters a nursing home earlier on average than a person with dementia who does not live alone.⁷ Long-distance caregivers also will benefit from patient navigation as they will receive trusted updates on their loved one's health, activities and safety. Finally, patient navigators also can assist significantly the high cost population of individuals with Alzheimer's who are dually eligible for Medicare and Medicaid and other individuals who have a history of bouncing among care settings due to behavioral issues, lack of family support, or added complications of multiple chronic diseases.

⁶ 2012 Alzheimer's Disease Facts and Figures Special Report on People with Alzheimer's Disease and Other Dementias Who Live Alone, Alzheimer's Association, http://www.alz.org/downloads/facts_figures_2012.pdf

⁷ 2012 Alzheimer's Disease Facts and Figures Special Report on People with Alzheimer's Disease and Other Dementias Who Live Alone, Alzheimer's Association, http://www.alz.org/downloads/facts_figures_2012.pdf

Reimbursement: funding a patient navigator program

Even with the prevalence of cancer patient navigator programs and the growing spotlight on care coordination, reimbursement for these services continues to prove challenging. The golden ticket for systematic implementation of patient navigation is establishing reimbursement through a major payer such as Medicare and Medicaid. Because the majority of people with Alzheimer's are Medicare members, it follows that Medicare is the ideal payer to target for implementation of an Alzheimer navigator program with corresponding reimbursement. Since Medicare is a federal program, changes to its reimbursement processes must occur at the federal level and likely will involve a combination of legislative, regulatory, and administration actions directed at the CMS. Such an accomplishment is no small feat.

The cancer community recently took a huge step forward in this effort when Centers for Medicare and Medicaid Services (CMS) established two Healthcare Common Procedure Coding System (HCPCS) codes for cancer treatment planning and coordination.⁸ These codes went into effect on April 1, 2012.⁹ Healthcare providers utilize these HCPCS codes when billing Medicare, Medicaid, and private insurance. For every service a medical practitioner provides and is able to bill for, there is a corresponding code. In order for a new code to be added, advocates must demonstrate that the services provided are distinct. The limitation on this recent achievement is that the practitioner must qualify as a healthcare provider who is eligible to bill services. Thus, the reimbursement likely will not cover all the components of the ideal patient navigation model because that model blends both social and clinical aspects of care. But, this breakthrough remains an option for a nurse-based model and may prove an effective way to chip away at the long-term goal of comprehensive coverage of patient navigation services.

Another approach is to direct advocacy efforts towards overhauling the current system. The Medicare fee-for-service program in which 80 percent of Medicare members participate currently does not pay for any care coordination services, while Medicare Advantage, which covers the remaining 20 percent of members, does pay for some care coordination services; however, these services are typically not as extensive as the patient navigation model.¹⁰ Although the addition of universal, basic care coordination reimbursement to Medicare is

⁸ HCPCS Release & Code Sets, Centers for Medicare and Medicaid Services, <http://www.cms.gov/Medicare/Coding/HCPCSReleaseCodeSets/index.html>

⁹ NCCS applauds establishment of cancer treatment planning and care coordination reimbursement codes, National Coalition for Cancer Survivorship, <http://www.canceradvocacy.org/news/nccs-applauds-establishment-treatment-care-reimbursement-codes.html>

¹⁰ Care Coordination, The American Geriatrics Society, http://www.americangeriatrics.org/advocacy_public_policy/care_coordination/

encouraged, the needs of a person with Alzheimer's are such that an Alzheimer-specific navigator program will provide them the best outcomes

Legislation may not be required to make these changes, but often a legislative message from Congress can cause CMS to make a change it previously resisted. A sample of recent federal legislation on this general topic includes:

- **Comprehensive Cancer Care Improvement Act of 2011 (H.R.3705/S.2097)**¹¹ creates reimbursement for cancer care planning. The legislation contains the findings "Changes in Medicare payment for comprehensive cancer care, enhanced public and professional education regarding symptom management, and more research related to coordination of care, symptom management and palliative care will enhance patient decisionmaking about treatment options and will contribute to improved care for individuals with cancer from the time of diagnosis of the individual through the end of the life of the individual." Alzheimer patient navigation services hold a similarly persuasive argument.
- **Health Outcomes, Planning, and Education for Alzheimer's Act (H.R. 1386/S.738)**¹² provides for establishing Medicare reimbursement for "care planning services (with the individual or with one or more family caregivers of the individual without the presence of the individual), including assistance understanding the diagnosis as well as the medical and non-medical options for ongoing treatment, services, and supports, and information about how to obtain such treatments, services, and supports." Although this legislation does not go as far as to include reimbursement for patient navigation, its enactment would stand as decisive step forward in improving support provided at diagnosis, a critical point for linking families up with Alzheimer patient navigators.
- **Reaching Elders with Assessment and Chronic Care Management and Coordination Act (H.R. 2307/S. 2009)**¹³ was introduced in the 111th Congress and would have established reimbursement for chronic care management and coordination services. This legislation has not been re-introduced.

¹¹ Comprehensive Cancer Care Act of 2011, <http://thomas.loc.gov/cgi-bin/query/z?c112:H.R.3705>:

¹² Health Outcomes, Planning, and Education for Alzheimer's Act, <http://thomas.loc.gov/cgi-bin/query/z?c112:H.R.1386>:

¹³ Reaching Elders with Assessment and Chronic Care Management and Coordination Act, <http://www.govtrack.us/congress/bills/111/s1004/text>

Another important, emerging vehicle that will help advance patient navigation in Alzheimer's disease is the newly released national Alzheimer's plan.¹⁴ It includes "Strategy 2.G: Advance coordinated and integrated health and long-term services and supports for individuals living with AD." It states that "Despite a general consensus that care coordination is important, more research is needed to determine how best to provide such care in a high-quality and cost-efficient manner." The plan lays out two key activities in working towards achieving this strategy: reviewing the evidence base on care coordination models for people with Alzheimer's and implementing and evaluating care coordination models for people with Alzheimer's, especially those individuals dually eligible for Medicare and Medicaid. The report identifies the new federal Integrated Care Resource Center¹⁵ as a key organization moving forward in working on care coordination models. The Integrated Care Resource Center states its role as providing technical assistance to "states in promoting seamless coordinated care, improving health care quality and patient outcomes, and reducing costs."

Other ways to fund navigation programs

Meanwhile, from the cancer world, a variety of creative financing methods exist for replication to help increase the availability of Alzheimer navigation programs, as well as the evidence base for these programs. Program proponents can pursue a variety of funding avenues, such as corporate, foundation, and organizational grants, federal research grants, hospital funding, and private employer programs. Frequently, hospitals fund cancer navigation through their operating budgets and tend to absorb the cost. Some private insurers employ their own patient navigators and also typically absorb the cost, although insurance company models often are not as robust and often do not involve face-to-face interactions. The other major funder of patient navigator programs is grants. Foundations like Avon and Susan G. Komen have funded multiple navigator programs. AstraZeneca, the pharmaceutical company, has pledged \$10 million to the American Cancer Society Patient Navigator Program.¹⁶ Additionally, the National Cancer Institute at the National Institutes of Health has awarded \$25 million in grants to eight research centers to study patient navigator models and help elevate the evidence base for these programs.¹⁷

¹⁴ National Plan to Address Alzheimer's Disease, Department of Health and Human Services, <http://aspe.hhs.gov/daltcp/napa/NatlPlan.pdf>

¹⁵ Integrated Care Resource Center, <http://www.integratedcareresourcecenter.com/>

¹⁶ First Anniversary of the American Cancer Society Patient Navigator Program at Dartmouth-Hitchcock's Norris Cotton Cancer Center in Manchester is celebrated, AstraZeneca News, <http://www.astrazeneca-us.com/about-astrazeneca-us/newsroom/6487376?itemId=6487376>

¹⁷ NCI Awards \$25 Million for Patient Navigator Research Program for Minority and Underserved Cancer Patients, National Cancer Institute, <http://www.cancer.gov/newscenter/pressreleases/2005/patientnavigatorgrants>
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As the National Plan to Address Alzheimer's Disease suggests, the Alzheimer community must build the evidence base for patient navigation, especially by showing that it decreases costs and increases quality by honing in on issues such as service duplication, unnecessary hospitalization or readmission, and inappropriate placement in more costly services.

Another potential source of support lies with the Patient Protection and Affordable Care Act (PPACA). Section 3510 instructs the Health Resources Service Agency to offer grant funding for patient navigator programs.¹⁸ This section reauthorized a program that previously funded six sites (none Alzheimer-specific), but funds have not been appropriated.¹⁹

A final report to Congress is due later in 2012 on CMS cooperative agreements with six sites evaluating the effectiveness in reducing ethnic/racial disparities in cancer screening and treatment by incorporating cancer patient navigator services.²⁰ The final findings could impact greatly the prospect for Medicare reimbursement for cancer navigation services and navigation services in general.

Finally, in May, UCLA's Alzheimer's and Dementia Care program received a \$3,208,540 award as part of the CMS Health Care Innovation Challenge program.²¹ A key part of the UCLA proposal includes training nurse practitioners as dementia care managers. These dementia care managers will in turn help train primary care providers and patient caregivers on dementia care. More information on this project should be available soon.

¹⁸ Patient Protection and Affordable Care Act, <http://www.healthcare.gov/law/index.html>

¹⁹ Patient Navigator Outreach & Chronic Disease Prevention Demonstration Program, Health Resources and Services Administration, <http://bhpr.hrsa.gov/grants/patientnavigator/outreachandprevention.html>

²⁰ Cancer Prevention and Treatment Demonstration for Ethnic and Racial Minorities Fact Sheet, Centers for Medicare and Medicaid Services, http://www.cms.gov/Medicare/Demonstration-Projects/DemoProjectsEvalRpts/downloads/CPTD_FactSheet.pdf

²¹ Health Care Innovation Awards: Project Profiles, Centers for Medicare & Medicaid Innovation, <http://innovations.cms.gov/initiatives/Innovation-Awards/Project-Profiles.html>

What states can do

Some states may be able to move more quickly in support patient navigation programs than the federal government. In addition to providing grant funding, states can work to make changes within their Medicaid programs or create their own patient navigation programs.

Section 2703 of PPACA authorizes an optional Medicaid state plan service for states to create health homes for members with chronic conditions and in return receive enhanced federal matching funds for two years.²² Alzheimer's disease is one of the eligible conditions that states may focus on. The health teams will coordinate enrollee's care needs, and "medical specialists, nurses, pharmacists, nutritionists, dieticians, social workers, behavioral health providers, chiropractics, licensed complementary and alternative practitioners" will comprise the teams.²³ Many states are in the process of crafting their state plan amendments to establish health homes, and some plans include people with Alzheimer's in their target populations. It may be possible, however, for a state to submit a state plan amendment solely or mostly focused on Alzheimer's disease and in build in enhanced Alzheimer patient navigation as a key service.

Another promising state-level intervention is the North Dakota Dementia Care Services Project. In 2009, the North Dakota Legislature appropriated funding to provide dementia care services across the state. The state elected to contract with the Alzheimer's Association, Minnesota/North Dakota Chapter to administer the program, which provides North Dakotans with dementia needs assessments and care plan development, resource identification and coordination, dementia education, and individual follow up services. From January 2010-June 2011, over 700 caregivers made almost 1,500 contacts with the service, and preliminary program evaluation illustrates positive outcomes, especially in the rural areas of the state, for obtaining healthcare directives and decreasing health and long-term care costs. These savings included decreased utilization of emergency rooms and 911 calls.²⁴ This program does not provide the intensive one-on-one services that true navigation program offers, however, the services it does provide appear to well-exceed the support currently offered by most states.

²² Patient Protection and Affordable Care Act, <http://www.healthcare.gov/law/index.html>

²³ Health Homes Overview, Centers for Medicare and Medicaid Services, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Integrating-Care/Health-Homes/Health-Homes.html>

²⁴ Dementia Care Services project: Continued Progress in Providing Assistance to Caregivers, Center for Rural Health, The University of North Dakota, http://ruralhealth.und.edu/pdf/0911_dcsp.pdf

Finally, states where Alzheimer's Disease Research Center are located possess a terrific opportunity for testing patient navigator models. Alzheimer's disease research centers have 30 locations in 19 states.²⁵ Centers are engaged in both Alzheimer research and diagnosis. As part of the diagnostic portion, most centers provide comprehensive support that mirrors the assessment and care plan development process of what an Alzheimer patient navigation program would provide. For example, the UC Davis Alzheimer's Research Center includes in its diagnostic evaluation service an assessment and care coordination piece led by nurses and social workers that contains "an in-home assessment of functional and safety concerns when indicated. A family conference is then held, summarizing the results and recommendations for care. Research participants are reassessed annually. Clinic staff remains available for consultation and support throughout the course of the illness."²⁶ Thus, one promising project could be to match the person with Alzheimer's and their family with a patient navigator at the diagnostic visit and then allow the navigator to work with them closely once they return to their community.

²⁵ Alzheimer's Disease Research Centers, National Institute on Aging, <http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers#UWash>

²⁶ Information About Services, UC Davis Alzheimer's Research Center, <http://alzheimer.ucdavis.edu/main/do.php>

Licensing and credentialing of patient navigators

As stated above, the fields of care coordination and patient advocacy include a variety of professional titles and job duties. Therefore, it is somewhat surprising that states have not stepped in and begun requiring the licensure of patient navigators and similar professionals to ensure that minimum qualifications exist and are adhered to. This absence in part may be due to the fact that most patient navigators already are state licensed social workers, nurses, and mental health professionals whose primary license already requires them to work within a certain scope. Additionally, without a consistent reimbursement mechanism, states may view the need for licensure as less pressing.

National professional associations for patient navigators and other categories of health advocates do exist and include the National Association of Healthcare Advocacy Consultants and the National Association of Professional Geriatric Care Managers. Both organizations maintain a Code of Ethics. In addition to membership benefits, these associations also assist consumers with locating professionals providing navigation and coordination services in their local area.

Currently, a dearth of formal patient navigation degree programs exist, however, it is likely that more programs will start in the near the future, as the education system catches up with the healthcare system and reimbursement becomes more common. Sarah Lawrence University in New York offers a master's degree in patient advocacy, while a few undergraduate institutions now offer certificates in patient advocacy. An array of online and convention-based programs also exists that allow a person to become "certified" or "receive a certificate in" patient navigation, advocacy, care coordination, etc. It is unclear what value these types of program hold for the recipient and whether employers and families assign any importance to them. Further, the quality of training received through these programs likely varies. Finally, programs like the Alzheimer's Association's essentiALZ™ dementia care certificate program focus mostly on dementia care education and less on the other essential parts of navigation services, understanding the healthcare systems and working as a part of an interdisciplinary group of health professionals.²⁷

Conclusion: Alzheimer patient navigation: an idea to move forward

Great opportunity lies ahead to test the efficacy of Alzheimer patient navigation models because in the near future, significant funding likely will become available. However, the long-term challenge is demonstrating to the healthcare system that patient navigation not only works, but that Alzheimer's is a unique disease that requires a specialized set of navigation services and that generic care coordination services are insufficient.

²⁷ essentiALZ™ Program, Alzheimer's Association, <http://www.alz.org/essentialz/#jump1>

Patient Navigation: Annotated Bibliography

Introduction: A systematic search was conducted on PubMed dated from 2000 to the present in order to determine whether patient navigators produced positive outcomes in various stages of care: prevention, screening, and treatment. 20 peer reviewed articles were selected and from there, 6 were chosen that encompassed a variety of methodologies. Both qualitative and quantitative research was included. The annotated bibliography begins with editorials and then moves to randomized controlled trials among a variety of populations. In what you see that follows will be a brief introduction of each article, its key points, and a concluding statement and how it may be applicable to dementia or Alzheimer's disease.

Fischer, S.M., Sauaia, A., Kutner, J.S. (2007). Patient navigation: A culturally competent strategy to address disparities in palliative care. *Journal of Palliative Medicine*, 10(5), 1023-1028.

In order to overcome barriers to the healthcare system, patient navigators are often utilized when assisting patients to help access quality care and treatment. This paper addresses how the traditional patient navigator model can be applied to palliative care with the example of improving seriously ill, older Latino's pain management.

- No standard definition of a patient navigator exists but common activities include:
 - Facilitate care and treatment, provide education and emotional support, assist with outreach and advocacy, and provide assistance with other needs such as transportation and language interpretation.
- There is a need for patient navigation in palliative care for numerous reasons, especially among ethnic minorities due to the disparities they face.
 - Minorities have limited understanding of advance care planning; higher rates of institutionalized death, lower hospice utilization rates, and more untreated or undertreated pain management.
- A recently funded project involves a randomized controlled trial of a patient navigator program to improve pain management for older, seriously ill Latinos.
 - The patient navigator is a bicultural Latina navigator to provide culturally and linguistically appropriate guidance through the healthcare system at the end of life with advanced care planning, pain management, and hospice.
 - This navigator will participate in outpatient visits with the patient to help convey treatment options and assist in the completion of advance care directives and ensure that they are scanned into the patient's medical record. Additionally, they will help with practical needs by connecting the patient with community resources.

This article is a nice overview of what a patient navigator is and their role in palliative care. The main point is the authors found a lack of standardization for the profession and there are diverse definitions that are used to describe their role. The authors conclude that a barrier-based definition should be used. This can be applicable to patients with Alzheimer's disease, especially in the later stages as they and their caregivers face end of life planning.

Freeman, H. (2006). Patient navigation: A community based strategy to reduce cancer disparities. *Journal of Urban Health*, 83(2), 139-141.

The American Cancer Society (ACS) has found that there are significant barriers among low-income people in terms of cancer screening, diagnosis, and treatment. Furthermore, because of late diagnosis and treatment, they experience greater pain and suffering and have a higher prevalence of death. They often do not seek care because of financial constraints and are overwhelmed by the healthcare system therefore, are more likely to be fatalistic and give up hope when it comes to accessing care.

- The author, Dr. Harold Freeman, instituted the first ever Patient Navigation Program in 1990 at the Harlem Hospital Center in New York which acted as a model for legislation, the "Patient Navigator Outreach and Chronic Disease Prevention Act," that was enacted in 2005.
- Harlem Hospital studied low-income women's breast cancer survival rates during two time periods (pre- and post-patient navigator implementation).
 - There were 606 patients (94% African American) with breast cancer from 1964-1986. A majority was of low socioeconomic status and about 50% had no health insurance. At the time of diagnosis, about half of the women were in stage 3 or 4 and their 5 year survival rate was 39%.
 - At the same hospital in a separate study from 1995-2000, 324 women were treated for breast cancer with the involvement of a patient navigator. 70% of the women were black and 26% were Hispanic. Like the earlier study, most were of low SES and about 50% were uninsured. However, there was an improvement in their stage of breast cancer at the time of diagnosis, and the 5 year survival rate was 70%.

Not only did the program provide free or low cost mammography screening, but patient navigators aided in outreach activities and provided culturally sensitive education. The patient navigators were also involved in helping reduce barriers patients encountered when trying to access screening and timely treatment. Dr. Freeman feels as though the Patient Navigation Program proved to be a significant factor in Harlem Hospital patients' improved outcomes. The Patient Navigator Outreach and Chronic Disease Prevention Act provides grants to entities to implement patient navigator systems and may be a viable source of funding to look into pilot programs with Alzheimer patients.

Dohan, D., Schrag, D. (2005). Using navigators to improve care of underserved patients. Current practices and approaches. *Cancer*, 104, 848-855.

The authors from this article look to define patient navigators and discover how they are organized in order to develop a framework for future methods and initiatives. A literature review was conducted but due to the lack of published peer-reviewed articles, the authors collected their own original data through qualitative research.

- Direct observation was conducted at a California outpatient oncology clinic that has a locally funded patient navigator program with predominately low-income patients. In-person interviews were conducted at the same site with patients, providers, and navigators.
 - Patient navigators were utilized in a variety of ways. Some addressed language and cultural barriers, aided with screening, provided emotional and social support during clinic visits and treatments, gave information and clarification to address patients' mistrust in the healthcare system, and helped with practical barriers such as transportation and childcare.
- In order to gain a broader perspective of patient navigators outside California, telephone interviews were conducted with patient navigators from federally funded programs through the National Cancer Institute.
- Through the literature review and data collection, no standard definition was determined however, the authors felt as though a barrier-focused definition was needed, not a definition centered on services.
 - They discovered that navigators play a more reactive role and fix patients' problems as they come. Patient navigators were more often than not welcomed from patients and families but providers felt their services and advice they provided went outside their area of expertise.

Like the article by Fischer et al., the authors suggest a barrier-focused definition for patient navigators. Their suggestion to conduct randomized controlled trials with patient navigators is utilized by the proceeding authors. Further information is still needed on data that proves the cost effectiveness of navigators. Results that indicated patient navigators were welcomed from patients and families have strong implications for Alzheimer's disease and the support families and caregivers will need through the course of their loved one's disease management and treatment.

Ferrante, J.M., Chen, P.H., Kim, S. (2007). The effect of patient navigation on time to diagnosis, anxiety, satisfaction in urban minority women with abnormal mammograms: A randomized controlled trial. *Journal of Urban Health*, 85(1), 114-124.

The effectiveness of a patient navigator on outcomes related to improving care among minority women with abnormal mammograms is examined in a randomized controlled trial at an urban hospital. The authors hypothesize the utilization of a patient navigator will increase trust, offer emotional support, and help better navigate the health system which will lead to better outcomes such as faster time to diagnosis, decrease in patients' anxiety, and increase in levels of satisfaction.

- The study design was a randomized controlled trial.
 - 105 participants were randomly assigned to one of two groups.
 - The control group received usual care while the intervention group received usual care plus patient navigation.
- The patient navigator assisted with appointment scheduling, offered emotional and social support, directed patients to financial assistance, served as a liaison between the patient and provider, and ensured resources and support services.
- Outcomes were consistent with authors' hypotheses.
 - The intervention group had shorter diagnostic intervals. 22% of women in the control group did not have a final diagnosis at 60 days compared to 6% in the intervention group. The average time to diagnosis was 42.7 days in the control group and 25.0 days for women who had a patient navigator.
 - Anxiety levels were similar for women in both groups at baseline but after diagnosis; the mean anxiety index was lower for the intervention group.
 - Satisfaction score was similar with women in the intervention group reporting higher levels of satisfaction (encounters with staff, waiting times, accessibility of staff via telephone, transparency of information provided, etc.).

The takeaway point is a randomized controlled trial supported the effectiveness of patient navigators during the early stages of diagnosis and care for women with breast cancer. However, the sample size was rather small with 36% of eligible women participating. The most common reason for refusing to participate was distrust. The improvement in anxiety levels and satisfaction scores might be able to be translated to Alzheimer patients and their families.

Carroll, J.K., Humitson, S.G., Meldrum, S.C., Salamone, C.M., Jean-Pierre, P., Epstein, R.M., Fiscella, K. (2010). Patients' experiences with navigation for cancer care. *Patient Education and Counseling*, 80, 241-247.

Little research has been done to study patients' experiences with patient navigation during their cancer-care. The authors define patient navigation to encompass instrumental and emotional support for patients and seek to discover how patients' experiences differ between those who receive patient navigation and those who do not. They also address which aspects of navigation patients value the most.

- In a randomized controlled trial, 35 interviews were conducted among those who screened positive or were diagnosed with colorectal or breast cancers.
 - Participants were interviewed either within 2 weeks of their cancer treatment completion or one year from the time of enrollment.
 - 19 patients were randomized to the group that had a patient navigator. Almost 80% of patients were white and about 75% had insurance.
 - Patient navigators were lay community members that went through various training.
- Patients' expectations for their instrumental needs:
 - The most common expectation reported was the patient navigator would provide instrumental needs, more specifically information-giving.
 - Patients hoped for assistance with insurance coverage, transportation, and what to expect.
- Patients' expectations for their emotional support:
 - Many patients reported expecting to feel overwhelmed and wanted their navigator to provide emotional and social support.
- Patients felt the most valuable aspect of their navigation was among the theme of emotional support or "being there."
 - Emotional support consisted of social support and served as a source of comfort when navigators would call to "check in" and drop by for informal visits.
 - Information-giving was also reported to be a valued aspect when navigators would help with administrative challenges and acted as a resource.

This qualitative study goes in depth of patients' expectations and outcomes after guidance from a patient navigator during their cancer-care. It is helpful to understand what patients particularly desired and valued from their navigator. Patients reported emotional support as the most meaningful aspect of navigation. Patients who did not have a patient navigator reported feeling more isolated, overwhelmed, and had less support during the process. This can be applied to Alzheimer patients, especially family members or caregivers' instrumental and emotional needs.

Jandorf, L., Gutierrez, Y., Lopez, J., Christie, J., Itzkowitz, S.H. (2005). Use of a patient navigator to increase colorectal cancer screening in an urban neighborhood health clinic. *Journal of Urban Health*, 82(2), 216-224.

The use of a patient navigator is studied to determine whether the incidence of colorectal cancer (CRC) screening increases within 6 months of a physician recommendation. A barrier for patients, especially minority patients to CRC screening is their perception of the difficulty to navigate the complex healthcare system.

- The study design is a prospective clinical trial.
 - 78 participants in an East Harlem, New York primary care clinic were recruited to participate.
 - Most participants were female (74.4%), minorities (82.1% Hispanic), and low-educated (11.5% had at least a high school degree).
- One patient navigator was recruited from the community who shared a similar ethnic background as the participants.
 - Participants were randomly assigned to the intervention group that received services by the patient navigator or the control group who received no patient navigator services.
 - The navigator assisted the patient with scheduling, provided written reminders about screening, and delivered education about CRC.
- 15.8% of participants in the intervention group completed an endoscopic examination within 6 months of a physician recommendation versus 5% in the control group.

The study population is above the age of 50 with a mean age of 61.2. Because of the older population, lessons learned may be applicable to dementia or Alzheimer patients in the early stages of diagnosis. However, this study only looked at screening and no treatment methods for CRC.

Additional Sources

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Conclusion

Lessons learned from reviewing the literature prove patient navigator systems to be a promising area to explore, especially with dementia and Alzheimer's disease. Results, particularly with the randomized controlled trials were consistent in patients who received guidance from a patient navigator as they had better outcomes among their different stages of care. What is missing from the research, however, is information on how patient navigators can assist patients specifically with dementia or Alzheimer's disease and the effect their services have on caregivers as well. In the future, should the model become adopted into the mainstream of Alzheimer care, it would be interesting and beneficial for the field to gather data to determine how the two would intersect and the outcomes it would produce.