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Implementing Dementia Care Models in Primary Care Settings: The Aging Brain Care Medical Home (Special Supplement)

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Abstract

Objectives—The purpose of this paper is to describe our experience in implementing a primary care-based dementia and depression care program focused on providing collaborative care for dementia and late-life depression.

Methods—Capitalizing on the substantial interest in the US on the patient-centered medical home concept, the Aging Brain Care Medical Home targets older adults with dementia and/or late life depression in the primary care setting. We describe a structured set of activities that laid the foundation for a new partnership with the primary care practice and the lessons learned in implementing this new care model. We also provide a description of the core components of this innovative memory care program.

Results—Findings from three recent randomized clinical trials provided the rationale and basic components for implementing the new memory care program. We used the reflective adaptive process as a relationship building framework that recognizes primary care practices as complex adaptive systems. This framework allows for local adaptation of the protocols and procedures developed in the clinical trials. Tailored care for individual patients is facilitated through a care manager working in collaboration with a primary care physician and supported by specialists in a memory care clinic as well as by information technology resources.

Conclusions—We have successfully overcome many system-level barriers in implementing a collaborative care program for dementia and depression in primary care. Spontaneous adoption of new models of care is unlikely without specific attention to the complexities and resource constraints of health care systems.

Keywords

Dementia; primary care; late life depression; implementation science

Introduction

According to the Institute of Medicine, it takes an average of 17 years for only 14% of new scientific discoveries to enter clinical practice.(Balas & Boren, 2000; Institute of Medicine & Committee on Quality of Health Care In America, 2001) Randomized clinical trials demonstrate the effectiveness of collaborative care in improving outcomes for older adults with depression, dementia, and other chronic medical and mental health conditions.(Bruce et al., 2004; Callahan et al., 2006; Counsell et al., 2007; Gilbody, Bower, Fletcher, Richards, & Sutton, 2006; Institute of Medicine, Committee on the Future Health Care Workforce for Older Americans, & Board on Health Care Services, 2008; Kroenke et al., 2007; Magnabosco, 2006; Unutzer et al., 2002; Vickrey et al., 2006; Williams et al., 2007) Despite the effectiveness of these new models of care, there are multiple barriers to their widespread adoption, and most older adults with mental illness do not have access to these interventions. (Boustani, Sachs, & Callahan, 2007; Institute of Medicine et al., 2008) While translational research seeks to overcome barriers between “bench to bedside” and between “bedside to clinical care”, there is also a translation gap between clinical care in the research setting and clinical care in actual community practice.(Westfall, Mold, & Fagnan, 2007) Overcoming this gap is particularly difficult for multi-faceted interventions requiring fundamental practice redesign, such as mental health collaborative care models.(Boyd et al., 2005; Institute of Medicine & Committee on Quality of Health Care In America, 2001; Jencks et al., 2000; Pham, Schrag, Hargraves, & Bach, 2005)

Implementation research has been defined as: “a body of knowledge on methods to promote the systematic uptake of new or underused scientific findings into the usual activities of regional and national health care and community organizations, including individual practice sites.”(Rubenstein & Pugh, 2006) Implementation science builds from methodology developed for controlled clinical trials, but tends to emphasize local adaptation rather than rigid protocols. (Unutzer, Powers, Katon, & Langston, 2005) This work also requires access to a clinical laboratory more representative of real-world clinical practice. A common approach to satisfying the need for a new type of laboratory has been community-based participatory research. Community-based participatory research recognizes the importance of involving the end-user (the targeted community) in the design, implementation, and evaluation of local efforts to adopt and adapt new scientific knowledge. While it is important to understand the key components and design of memory care clinics, it is also important to understand the problems and prospects of building local support and resources to establish these new clinics.

The purpose of this paper is to describe our experience in building a partnership with a community-based health care institution in the United States to establish a primary care-based dementia care program focused on providing collaborative care for dementia and late-life depression. We call this program the Aging Brain Care Medical Home, or ABC Medical Home. Unlike the Healthy Aging Brain Center which is a free-standing memory care clinic described elsewhere in this issue, the ABC Medical Home provides a set of services integrated within the actual primary care practice. The Healthy Aging Brain Center provides a base of operations for the outreach work of the ABC Medical Home. Because this outreach practice required a large investment in system redesign and in new partnership with primary care, this paper draws particular attention to the process of implementation.

In our initial deliberations regarding the design of this new dementia care program, we decided to target older adults with dementia or depression. There were four chief reasons for this decision. First, the conditions often co-occur and a recent report by the National Institutes of Health suggested that cognitive and emotional health should be studied

simultaneously.(Hendrie et al., 2006) Second, in our own clinical trials described later in this paper, we had found a frequent co-occurrence of these conditions regardless of whether the research condition of interest was dementia or depression. Third, successful care management of either condition requires attention to both because either could be the cause of symptoms or impairments. Fourth, local resource restraints and national payment policies are beginning to favor new models of care that target the patient rather than a single disease suffered by the patient.

In the Methods section, we describe our community partner, the collaborative care models that guided the program redesign and the perceived barriers to adoption of the new model of care. We describe the reflective adaptive process which served as the overarching methodological approach to building and sustaining the new partnership. In the Results section, we describe lessons learned in the implementation process. The description of this preparatory work is followed by a description of the ABC Medical Home and our negotiated evaluation framework.

Methods

Description of the Community Partner

Wishard Health Services is a tax-supported urban medical institution serving low-income patients in Indianapolis, Indiana in the US. Wishard is a member of the National Association of Public Hospitals and Health Systems, which represents more than 100 safety-net health care systems across the US. This safety-net system provides care to a large majority of Americans who are underinsured or uninsured. Over a four-year period, the community partner provided care to more than 30,000 adults aged 65 and older.(Callahan, Weiner, & Counsell, 2008) Prior research in the primary care clinics associated with Wishard Health Services demonstrated a prevalence of dementia and late life depression of approximately 6% each, but with low levels of recognition and treatment and poor outcomes in the usual care of these patients.(Boustani et al., 2005; Callahan et al., 2006; Callahan et al., 1994; Unutzer et al., 2002) We describe below three collaborative care projects that improved quality and outcomes of care. Understanding the content and results of these clinical trials is important to understanding the problems and prospects of implementing them in real-world clinical practice.

Description of Collaborative Care Models

“Project IMPACT” was a multi-site randomized controlled trial conducted among 1,800 primary care patients. Subjects were randomly assigned to a collaborative stepped-care program where a depression clinical nurse specialist worked with the patient’s regular primary care provider to treat depression using antidepressant medications and problem-solving therapy. The intervention was specifically designed to coordinate care for depression with the patient’s regular primary care provider. Intervention patients were significantly more likely to receive guideline-level care, to recover from depression, and to report improvement in physical function, health-related quality of life, and satisfaction with care. (Callahan et al., 2005; Harpole et al., 2005; Katon et al., 2005; Unutzer et al., 2002) Other depression care management models reported similar promising outcomes.(Bruce et al., 2004; Dietrich et al., 2004) Project leaders have subsequently led substantial efforts to promote uptake of this new model of care across the US.(Unutzer et al., 2005)

Building from lessons learned in Project IMPACT, our research team designed a collaborative care intervention based on current treatment recommendations to improve the recognition and treatment of Alzheimer’s disease in primary care. (Boustani et al., 2005) (Callahan et al., 2006) We completed a controlled clinical trial of 153 older adults with

Alzheimer disease and their caregivers who were randomized by physician to receive collaborative care versus augmented usual care. Both study groups completed a counseling visit with an advanced practice nurse who provided education about Alzheimer disease and referral to community resources. Over the following year, intervention patients received care management by an interdisciplinary team led by a nurse practitioner working with the patient's family or caregiver. (Austrom et al., 2004) Intervention subjects were more likely to rate their primary care as very good or excellent. Intervention patients also had significantly fewer neuropsychiatric symptoms at 12 months. Caregivers, too, reported significant improvements in distress. Other care management clinical trials have also shown improvement in the quality of care provided to older adults with dementia. (Vickrey et al., 2006)

In a recently completed clinical trial, we significantly expanded the primary care reach and scope of collaborative care into the homes of vulnerable older adults and across multiple geriatric syndromes. We tested the effectiveness of a care management model that integrated care for multiple chronic comorbid conditions and provided for in-home support and education. Intervention patients received two years of home-based care management by a nurse practitioner and social worker who collaborated with the primary care physician and a geriatrics interdisciplinary team and were guided by 12 care protocols for common geriatric conditions. This integrated and home-based geriatrics care management resulted in improved quality of care and health-related quality of life. (Counsell et al., 2007)

Barriers to Spontaneous Adoption of Collaborative Care Models

In early conversations with the community partner, we discussed why the health care system had not already acted on collaborative care evidence available in the literature. There are, of course, numerous barriers to the adoption of collaborative care models from the perspective of the community partner. For example, the clinical practices simply do not have the financial resources to build such programs, and there is only partial evidence that such programs can save money or be cost-neutral. Given its role as a safety-net provider, our community partner faces financial challenges to new program development, including investment for startup costs. (Wolff & Boulton, 2005) Thus, the health system may need to look for cost-offsets or cost savings that would help provide a financial rationale for the new programming. (Counsell, 2009) In addition to financial costs, clinical practices must consider space constraints, patient flow, provider's other roles, the patient-physician relationship, information technology, cultural barriers, and the overall organizational acceptance or resistance to change. (Grumbach & Bodenheimer, 2002) Finally, there are many unmet needs within the targeted patient population of which mental health care among older adults is only one. For these reasons, unmet needs that have a vocal champion, that can generate resources, and that fit within the existing organizational structure tend to have a much greater opportunity for both adoption and long-term sustainability.

Conceptual Framework Guiding the Construction and Maintenance of the Partnership

Traditional organizational theory leads us to view health care systems as machine-like structures with replaceable parts. These machine-like structures are believed to exhibit behaviors that can be predicted based on past performance. (Anderson, Crabtree, Steele, & McDaniel, 2005; Morgan, 1986) This view assumes that stability is the natural state of these systems; that health care systems consist of functions that are carried out by replaceable employees; and that financial incentives, regulations, and evidenced-based practice information are the recipe for improving performance. (Anderson et al., 2005) Prior research shows that these efforts often fail due to the unique or idiosyncratic local interactions of patients, employees, resources, and other demands. (Anderson et al., 2005; McDaniel, Jordan, & Fleeman, 2003) The "Reflective Adaptive Process" has been proposed as an

alternative approach to allow local health care systems to adapt and adopt new knowledge. (Cohen et al., 2004; Crabtree, Miller, & Stange, 2001; DOPC, 2001; Stroebel et al., 2005) Reflective adaptive process facilitates the development of local strategies. (Stroebel et al., 2005) There are five guiding principles to the reflective adaptive process:

1. Vision, mission, and shared values are fundamental
2. Creating time and space is necessary for systems to adapt to and plan change
3. Tension and discomfort are essential and normal
4. Improvement teams should include a variety of system's agents, including patients
5. System change requires supportive leadership that is actively involved in the change

We initially envisioned a retreat-type seminar or conference where program leaders would assemble all stakeholders and end-users and indoctrinate them in the reflective adaptive process. A product of this retreat was to be the locally negotiated adaptation of the collaborative care models. For numerous practical reasons, and because of the organic nature of the program adaptation and implementation, such a time-limited or cross-sectional approach is both ineffective and impractical. In practice, we implemented the reflective adaptive process in a snowballing fashion where we first engaged project stakeholders in key leadership positions and then began widening this circle to successive layers of end-users.

Results

Progress and Pitfalls in Implementing the Reflective Adaptive Process

1. Vision, mission, and shared values are fundamental—Reaching a shared vision, mission, and shared values was relatively straightforward. Within this broad agreement, however, we encountered three important initial hurdles. First, a majority segment of Wishard Health Services' clinical responsibilities and resources are devoted to the care of children, while the majority segment of the academic partners' research enterprise is devoted to improving the care of older adults. Second, our "community partner" actually consists of a matrix of semi-autonomous, interdependent organizations including a large physician-led group medical practice (which itself consists of multiple specialties and multiple sites of care). Third, external forces ranging from payors to regulators to patient advocacy groups continually shape and re-shape the community partner's priorities. The concomitant macro-level changes not only compete for the community partner's attention and resources, they also cloud the capacity to measure the impact of the implementation project.

2. Creating time and space is necessary for systems to adapt to and plan change—In many respects, none of the other principles of the reflective adaptive process (or the implementation process) can succeed without the time and space for the stakeholders to build a relationship in support of change. Given the complexity of the matrix of stakeholders represented by both the community and the academic partner, implementation researchers will find it difficult to maintain a reasonable size for the leadership group. The difficulty is not in identifying who should be at the stakeholder table but identifying the time when all can be available. In practice, our implementation project began to suffer from the tyranny of time and space for meetings. If one closely adheres to a goal to have all key players around the same table, the project quickly loses momentum. The primary problem is not that stakeholders cannot agree to a mutually suitable time (although this is daunting). The larger problem is that the competing macro-level forces faced by the community partner may demand crisis intervention. Thus, time and space for stakeholders to build a relationship

is simultaneously essential and paralyzing. Our local solution was to schedule two separate meetings among 14 different stakeholders and allow these stakeholders to attend the meeting that best fit their schedule.

3. Tension and discomfort are essential and normal—Avoiding conflict is not a realistic goal when partnering with health care systems to implement quality improvement efforts. The quality of the relationship effectively can be judged by assessing the team’s capacity to manage conflict. If conflict management is a prerequisite for a successful partnership, then mutual respect is a prerequisite for successful conflict management. Mutual respect, in turn, requires time and space. Tensions and lack of trust may also emanate from “outside the room” because the stakeholders around the table for the implementation project nearly always have a conflict relationship around other projects within the health care system. In practice, the lack of tension and discomfort must be viewed as important warning signs that the partnership is failing. Notably, the presence of tension and discomfort is not necessarily evidence that the partnership is succeeding. Thus, tension and discomfort are essential and demonstrate the health of the relationship, but the origins of this tension and discomfort must be continually and transparently investigated.

4. Improvement teams should include a variety of system’s agents, including patients—In principle, stakeholders agreed that the end-users play a fundamental role in the success or failure of quality improvement. There are important examples of major quality improvement programs failing due to the inadequate inclusion of the end-users or failure to account for other important contextual variables.(Grimshaw et al., 2006; Hagedorn et al., 2006; Hendy, Fulop, Reeves, Hutchings, & Collin, 2007; Hendy, Reeves, Fulop, Hutchings, & Masseria, 2005; Kochevar & Yano, 2006) Problems arise, however, in determining the timing and level of involvement of end-users. If the timing is too late, end-users may feel disenfranchised and if too early, some end-users fear they will be identified as a “decision-maker” among their peers and thus responsible for potentially unpopular changes.

5. System change requires supportive leadership that is actively involved in the change—Leaders actively demonstrated their support through participation in “time and space” meetings, allocation of financial and facility resources, and cheerleading in forums outside those designated for time and space meetings. Although the first two activities may be self-evident, the third attends to what has often been termed “the hidden curriculum”.(Hafferty, 1998; Snyder, 1970) Attention to the hidden curriculum must include key stakeholders as well as other key opinion leaders who may or may not be formal leaders. Notably, the hidden curriculum can be used to advance or undermine any quality improvement activity. Thus, it does not necessarily denote a negative force of change.

In practice, one of the most influential components of the hidden curriculum in our partner organization is the potential for a mismatch in what leaders say is valued as compared to what is measured in performance evaluations, accounted for in financial evaluations, or accommodated in resource allocations. For example, if the health care system truly values objective assessment of outcomes of mental illness in primary care, then end-users would expect that such activities would be afforded resources and assessed in quality or cost evaluations.

Negotiated Quantitative Framework

Although our academic-community provider partnership began with the goal of implementing an integrated collaborative care model for late life depression and dementia, a different language emerged from the reflective adaptive process. Multiple stakeholders and

end-users from the community partner began responding to the tidal wave of interest in the “patient-centered medical home”. As anyone contemplating system-level changes in primary care in the US between 2005 and 2009 would recognize, the medical home became a widespread movement for the redesign, reengineering, and re-financing of primary care. The key components of a medical home include: a personal physician working in collaborative with a team of health care professionals; a whole person orientation; care that is coordinated and integrated; care that is safe, effective, and evidence-based; enhanced access to care; and payment that recognizes the added value of the medical home approach. (American College of Physicians, 2006; Grumbach & Bodenheimer, 2002; Rosenthal, 2008; Sia, Tonniges, Osterhus, & Taba, 2004) Typically, a medical home would require coordinated care across the continuum of care, which would typically require the appropriate use of information technology including health information exchanges, computer-based decision-support, clinical registries, and longitudinal tracking of the outcomes of care.

Fortuitously, collaborative care models targeting multiple chronic illnesses are well within the minimum specifications of the patient-centered medical home. In addition, collaborative care or care management provides a blueprint for initiating a medical home model. Thus, over a year of the reflective adaptive process, our collaborative care model was recast as the Aging Brain Care Medical Home. This has fundamental implication for key metrics of success from the perspective of the community partner. Financial metrics of success must be weighed in addition to metrics typical of clinical trials such as patient-specific clinical outcomes, satisfaction, safety, and quality of care. In essence, the upfront costs of improving patient outcomes through the medical home model would ideally be offset through downstream savings in high-cost utilization patterns such as emergency department use, hospitalizations, re-hospitalizations, inappropriate diagnostic or therapeutic services, or institutionalization. Current demonstration projects supported by Medicare, for example, seek to examine the potential of alternative methods of financing medical home models. (Barr, 2008; Fisher, 2008; Rittenhouse & Shortell, 2009; Rosenthal, 2008; Starfield & Shi, 2004) This potential for new financial models greatly increased the potential for long-term adoption of the Aging Brain Care Medical Home.

Description of the ABC Medical Home

The goal of the ABC Medical home is to identify, evaluate, and manage the biopsychosocial needs of older adults suffering from dementia and/or depression and their family caregivers. The target patient population is older adults who receive their primary care from clinical practices affiliated with Wishard Health Services. The table at right summarizes the locally negotiated minimum care components of the ABC Medical Home. The core components reflect the same care delivery components targeted in the Healthy Aging Brain Center. In the context of the ABC Medical Home, the care manager is working directly with the primary care physicians and within their suite of offices to facilitate this care.

Thus, the role of the care manager is to tailor and facilitate the delivery of these components to individual patients in collaboration with the primary care physician. Prior collaborative care models have used care managers from a variety of disciplines including nurses, social workers, and psychologists, among others. However, discussions about the local implementation of the dementia care managers resulted in a decision to employ an advanced practice nurse in this role. The advanced practice nurse has enhanced training in diagnosis and treatment of chronic conditions and also has prescriptive authority. These health care professionals have also developed a high level of credibility within the targeted primary care practices and thus are accepted as co-managers of primary care patients. In addition to their background in nursing, these care managers can also be provided additional training in: accessing community resources, providing brief problem-solving psychotherapy, medication management, the care of older adults with dementia and depression, and counseling and

caring for family caregivers. The advanced practice nurse is supported in these roles by a medical director who is a physician with special expertise in the care of older adults with dementia and depression. The medical director also serves as the primary liaison with the health care system leadership. Both the care manager and the medical director have access to an administrative assistant who is dedicated half-time to the ABC Medical Home activities.

In order to efficiently deliver the components of the ABC Medical Home, the care team is supported by an array of information technology tools. These tools include a laptop with wireless access to both the local intranet and the internet, a workstation with access to computerized order-entry and electronic medical records; electronic capture and storage of patient outcome data including functional, behavioral, psychological, and cognitive symptoms; a web-based tracking system to support care coordination, and a telephone/email system to communicate with caregivers, patients and providers. Recognizing the space limitations of primary care, the care coordinator utilizes patient examination rooms in conjunction with the other providers of care in the primary care suite of offices. However, the information technology described above provides the case manager with the flexibility to deliver care and access needed data in other clinical settings with the health care system, in facilities outside the health care system (e.g. skilled nursing facilities) and in the patient's home. Finally, the case manager has access to an office and dedicates approximately 50% of her time to care coordination activities that do not involve face-to-face interactions with patients.

The Minimum Care Delivery Components of the ABC Medical Home

1. A reliable tool for periodic needs assessment and evaluation of ongoing therapy
2. Pharmacological and psychosocial interventions that prevent or reduce the family caregiver's psychological and physical burden
3. Self-management tools to enhance the skills of the patient and caregiver skills in managing symptoms and navigating the health care system
4. Pharmacological interventions for care-recipients that target the cognitive, functional, and behavioral and psychological symptoms
5. Enhancement of the patient's cholinergic system
 - a. prescribing cholinesterase inhibitors
 - b. decreasing exposure to anticholinergics
6. Improvement in medication adherence
7. Reduction in cerebrovascular risk factors
8. Antidepressants with no anticholinergic properties for major depression
9. Prevention and management of syndromes superimposed on dementia / depression (e.g. delirium, pain, and psychosis)
10. Case management and coordination with community resources:
 - a. adult day care
 - b. respite care
 - c. support groups
11. Modification of the patient's physical home environment to compensate for dementia related disability

Discussion

We describe our experience in building a community-based research partnership with a tax-supported urban medical institution in the US to facilitate the implementation of an integrated collaborative care model for dementia and late-life depression within a primary care practice. The Aging Brain Care Medical Home is now operational, and we are currently collecting evaluation data. Overall, we would conclude that the process was successful in the implementation phase but with three important lessons learned.

First, the laboratory, methods, and tools of implementation research are substantively different from those of clinical trials. Researchers and research programs who have demonstrated expertise and infrastructure for conducting controlled clinical trials are not necessarily equipped to conduct implementation research. This is also true for clinical and administrative counterparts who may have expertise in program development, health care administration, or quality improvement but have not prepared themselves or their infrastructure for implementation research. Perhaps the best example of this issue is the conflict-ridden statement: “We’re doing that already.” Often, “that” refers to an ineffective but inexpensive facsimile of collaborative care.

Second, time and space to build relationships are a fundamental requirement for implementation research and for community-based participatory research. Unfortunately, the amount of time and energy needed to build and maintain these relationships was substantially more than we anticipated. The excess time and timeline translate into excessive costs related to the conduct of implementation research. These costs can be measured directly in terms of the salary and related costs of senior researchers and health-system leaders. These costs can also be measured in terms of opportunity costs. The national resource of senior clinical researchers and health system administrators is already very limited. Retooling and reallocating this limited resource to implementation research should be done with considerable care.

Third, it is difficult to over-estimate the impact of external forces on the success, evaluation, and relevance of implementation projects. Changes in Medicare payments policies, for example, can speed, slow, or kill implementation projects regardless of any local efforts. There are many more subtle external forces that influence the outcomes of implementation research. This is precisely why the typical clinical trial research project shields itself from these forces and precisely why the results of clinical trials often are not relevant to day-to-day clinical practice. Some of these forces, such as the patient-centered medical home movement, represent a vehicle to facilitate successful implementation.

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