"Guided Care" for People with Complex Health Care Needs

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Introduction

One-quarter (24 %) of Americans have two or more chronic conditions. Their health care is often fragmented, of low quality, inefficient, and unsatisfactory to them, their families, and their physicians. The Institute of Medicine has described chronic care in America as "a nightmare to navigate." People with multi-morbidity are also at high risk for generating high health care expenditures: 96 % of the US Medicare budget is spent on beneficiaries with multiple chronic conditions.

Several flaws in the infrastructure of the US health care system underlie these problems: inadequate professional education, inconsistent use of information technology, payment incentives that drive high-volume rather than high-quality or high-efficiency care, lack of financial support for inter-professional communication and patient engagement in self-care, and multiple barriers to partnering with and supporting family caregivers.

Correcting these flaws will require numerous long- and short-term initiatives. Reforming health professional education, implementing interoperable health information technology, and migrating the focus of health insurance away from fee-for-service payments toward "value-based" payments for quality and outcomes will take many years. In the meantime, however, as millions of baby boomers reach retirement age each year, near-term improvements may be achievable by developing and adopting clinical models that improve outcomes for people with multiple chronic conditions in spite of the system's current infrastructural flaws. Some such models have shown promise [1–4], while others have failed [5] or not yet been tested rigorously.

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The Guided Care Model

Drawing from the chronic care model [6], guided care was designed to improve the quality of care and efficiency of resource use among older adults with complex health needs (Fig. 11.1).

In guided care, a registered nurse completes a 40-h online educational program and then works with two to five primary care physicians to meet the needs of 50–60 older patients with complex health care needs. Although the guided care nurse (GCN) supports patients across a range of institutional and community settings, the GCN is based in the primary care office to facilitate communication with the primary care physicians and office staff. The GCN's eight primary clinical activities, described below, are guided by scientific evidence and by patients' goals and priorities [7].

Patient and Family Caregiver Assessment

During an initial visit to the patient's home, the GCN begins by asking the patient to identify his or her goals and priorities for optimizing health and quality of life. Then the GCN assesses the patient's medical, functional, cognitive, affective, psychosocial, nutritional, and environmental status using standardized assessment instruments.

Care Planning

Based on the assessment results, the GCN then drafts a "preliminary care guide" that lists medical and behavioral plans for managing and monitoring each of the patient's chronic conditions to attain the patient's goals. The GCN and the

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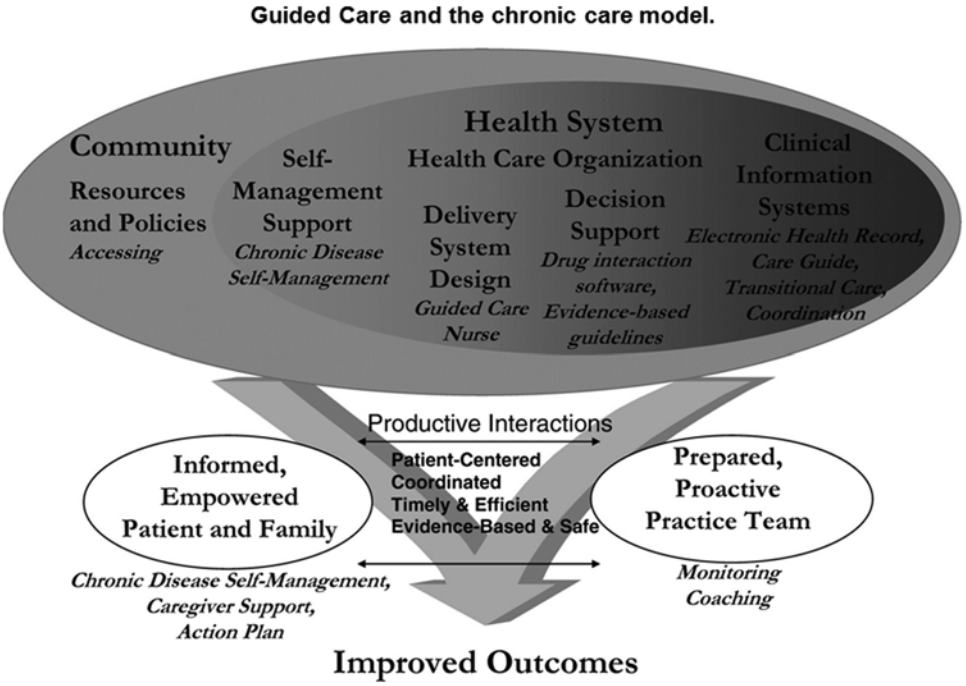

Fig. 11.1 *Guided Care Elements* in the Chronic Care Model (from Boyd C, Boult C, Shadmi E, Leff B, Brager R, Dunbar L, et al. Guided Care for multi-morbid older adults. The Gerontologist. 2007;47(5):697–704 with permission)

primary care physician then meet to discuss this preliminary care guide to align it with the circumstances of the patient. The GCN then discusses the preliminary care guide with the patient and the family caregiver, modifying it further for consistency with their goals, preferences, priorities, and intentions. The final care guide is a concise summary of the patient's status and care plans, which is later provided to all involved health care professionals. A patient-friendly version, called "My Action Plan," is written in lay language and displayed prominently in the patient's home. The GCN updates both documents as the patient's circumstances evolve.

Promotion of Self-Management

The GCN promotes the patient's self-efficacy in managing chronic conditions by referring him or her to a free, local, 15-h (six-session) course in "Chronic Disease Self-Management" (CDSM), if available, that is led by trained lay people and supported by the GCN. In this course, developed at Stanford University, the patient learns to refine and implement the action plan. Reinforced by simple, easy-to-read schedules and reminders, the action plan facilitates the patient's steps toward healthy eating, sleeping, exercising, and use of medication, as well as self-monitoring, using the health care system, and avoiding tobacco and alcohol abuse.

Monitoring Patients' Symptoms and Adherence

The GCN monitors each patient at least monthly by telephone to detect and address emerging problems promptly. When problems appear, the GCN discusses them with the primary care physician and takes appropriate action. In conjunction with the monthly monitoring calls, the GCN uses "motivational interviewing" to facilitate the patient's participation in care and to reinforce adherence to the action plan. The GCN expresses empathy, clarifies discrepancies between current behavior and health goals, seeks consensus, and supports self-efficacy.

Coordinating Providers of Care

Using the care guide as a communication tool, the GCN coordinates the efforts of all health care professionals involved in the patient's care across all care settings. Each patient is encouraged to share his or her care guide and action plan with their other health care providers and to inform his or her GCN of all encounters with other providers, so the GCN can track changes in plans and update the patient's care guide and action plan accordingly.

Smoothing Transitions Between Sites of Care

The GCN gives high priority to smoothing the patient's path between sites of care, focusing most intensively on transitions from hospitals to post-acute care, continually keeping the primary care physician informed of the patient's status. The GCN does not usurp the duties of other involved professionals, but instead provides each with current information about the patient, explains the GCN role, visits the patient in the hospital, and helps plan and execute post-acute care and return to the care of the primary care physician.

Supporting Family Caregivers

For the family caregivers of patients with functional impairment or difficulty with health care tasks, the GCN offers individual and group assistance: initial assessment, a free self-management course (10 h over 6 weeks), monthly support group meetings, and ad hoc telephone consultation [8].

Accessing Community Resources

The GCN facilitates access to community resources to meet the patient's and the family caregiver's needs. The GCN may suggest, for example, that the patient or family caregiver make use of a transportation service, Meals on Wheels, the Area Agency on Aging, or the local Alzheimer's Association.

Evidence That Guided Care Improves Outcomes

During 2006–2009, scientific investigators at the Johns Hopkins University conducted a matched-pair, cluster-randomized controlled trial of guided care versus "usual care" in eight community-based primary care practices operated by three large health care delivery systems in urban and suburban Baltimore, MD, and Washington, DC [9]. Six of the practices housed two teams apiece (two to five physicians per team); two of the practices, selected for their similarities, housed one team apiece. Three of the practices relied on capitated payments, while five received primarily fee-for-service payments. Additional study details are available in the scientific literature [10].

Selection of Physician Teams

Within the three delivery systems, teams of eligible physicians with panels of at least 400 patients aged 65 years or older and on-site office space for a GCN were eligible for the study. Primary care physicians within these teams were eligible to participate if they were board-certified general internists or family physicians who provided patient care at least 28 h per week. All 49 physicians within the 14 eligible teams agreed to participate.

Recruitment of Nurses

Applications from licensed registered nurses with at least 3 years of clinical experience were solicited by advertisements in local newspapers, the websites of the three participating delivery systems, and a regional nursing journal. Applicants with experience in geriatric nursing, interest in counseling patients in self-management, and comfort with interdisciplinary practice and information technology were given preference. Among the seven nurses hired, all were female, three were African-Americans, and four were Whites. The average age was 45 years (range = 32–57 years); the average nursing practice experience was 16 years (range = 4–31 years).

Recruitment of Patients

The physicians' patients were selected for initial screening if they were 65+ years old and insured through fee-for-service Medicare Parts A and B, a Kaiser Medicare health plan, or TriCare. Patients' health insurance claims from the previous 12 months were analyzed using the Hierarchical Condition Category (HCC) predictive model, which uses diagnosis codes to estimate a person's risk for generating high health care expenditures during the coming year. Patients were potentially eligible if their HCC risk scores were in the highest quartile of the population of older patients covered by their health care insurer.

High-risk patients were initially contacted by mail. A professional interviewer then called those who had not "opted out" to describe the study, answer questions, and offer an in-home enrollment meeting. At the enrollment meeting, interviewers described the study further, answered questions, and obtained written informed consent. Potential participants were deemed ineligible if they did not have a telephone, did not speak English, were planning extended travel, or failed a brief cognitive screen and did not have a proxy who could provide consent.

Randomization

Each team of physicians and their participating patients comprised a "pod." The study's statistician, blinded to the identities of the pods, used a random number generator to assign one pod from each pair (matched by practice) to the guided care group and the other to the "usual care" control group.

Results

Patients in 14 pods ($n=13,534$) were screened, and the 2,391 (17.7 %) who were eligible and available were offered study participation [9]. Of these, 904 (37.8 %) gave informed consent and were allocated to receive either guided care ($n=485$) or usual care ($n=419$). At baseline, the study participants' sociodemographic, functional, and health-related characteristics were similar, except that the "usual care" control group had slightly worse finances, physical and mental health, and IADL function, but its average risk of health care utilization was lower.

More than half (56.5 %) of all guided care recipients and 48.4 % of all usual care recipients completed the final interview. Complete claims data were available for 92.0 and 95.9 % of the guided care and usual care participants, respectively.

After 32 months, the adjusted aggregate quality of chronic care was reported to be significantly higher by patients with guided care than those with usual care (difference = 0.27; 95 % CI: 0.08–0.45). Guided care recipients were also more likely to report "excellent or very good" access to telephone advice (OR = 1.66; 95 % CI: 1.02–2.73) and being "very satisfied" with the care they received from their "regular" (primary) care teams, but this difference was not statistically significant (OR = 1.50; 95 % CI: 0.77–2.82).

Guided care had no statistically significant effects on self-rated health or on scores on the SF-36 mental health or physical health subscales. Compared to the usual care group, the guided care group used home health care at a 29 % lower rate (ratio = 0.71; 95 % CI: 0.51–0.97). Reductions of 6–26 % in the guided care group's utilization of hospitals and skilled nursing facilities did not reach traditional levels of statistical significance.

Physicians' satisfaction with their communications with patients and families and their satisfaction with management of chronic care increased relative to baseline more among physicians providing guided care than among physicians providing usual care, and these differences increased over time. As compared with usual care, staff members in guided care practices were more likely to report that the care provided to patients with complex health needs was patient centered [11].

Family caregivers' reports of the quality of the chronic illness care provided to their care recipients were higher with guided care than with usual care after 18 months of follow-up ($a\beta = 0.40$; 95 % CI = 0.14–0.67), a difference that was statistically significant ($p < 0.001$) [12].

Implementation in the Real World

Guided care improves the quality of chronic care, but the degree to which it reduces the utilization and costs of health care remains uncertain. The significant savings from reductions in the use of home health care would help to offset the costs of the intervention, but concomitant reductions (suggested, but not statistically significant in this small sample) in the use of hospitals and skilled nursing facilities would probably be necessary for the model to break even or reduce high-risk patients' net health care costs.

What lessons can we learn from this body of recent research that will help inform the next generation of comprehensive, interdisciplinary primary care for high-risk patients? Certain features are common to many of the more successful models, including systematic identification (and intensive management) of high-risk patients; primary care physicians collaborating with on-site registered nurses and other clinical staff members (all working in redefined roles "at the tops of their licenses"); health information technology that facilitates care coordination; engagement of patients and their family caregivers in self-management; easy 24/7/365 access to primary care for emerging problems; well-coordinated transitional care following hospital discharges; and the integration of community-based social and support services into health care.

Unfortunately, even models that have provided many of these features have produced only modest improvements in clinical and financial outcomes. Additional features, which have not been tested empirically but which could facilitate better outcomes in the chronic care models of the future, include well-run quality improvement processes in primary care practices; home tele-monitoring; close supervision of care managers to ensure their adherence to the model's priorities; and meaningful, risk-adjusted financial incentives for providers who provide high-quality care and achieve above-average outcomes with high-risk patients.

Accountable care organizations, comprehensive primary care providers, medical homes, and other health care delivery organizations are most likely to achieve meaningful improvements in chronic care by adopting (and judiciously adapting) care models with as many of these features as they can afford. Meanwhile, pragmatic studies of newer technologies, payment schemes, and models of chronic care will make further contributions to this rapidly evolving field. A wide range of innovations will be needed to create an economically sustainable system of health care and social services capable of meeting the rapidly growing, complex, health-related needs of the aging American population [9].

Barriers to Implementation

Practices and organizations that are interested in adopting this model need to determine whether they can meet five requirements.

1. *Panel size*: large enough to contain 50–60 patients with several chronic conditions. Panels of at least 300 Medicare patients are usually sufficient. Practices with larger panels may be able to support more than one GCN. Practices

with smaller panels could share a GCN if they were in close proximity to each other.
2. *Office space*: a small, private, centrally located office for the nurse. An ideal location is near the physicians' offices with convenient access to the practice's staff, medical records, supplies, and office equipment.
3. *Health information technology*: a locally installed or Web-based health information technology system that supports the GCN's activities.
4. *Commitment*: Practice's physicians and office staff members need to work collaboratively with the GCN. Integration of a new type of health care provider into a primary care practice is a process that requires careful planning, optimism, open communication, honest feedback, flexibility, perseverance, and patience.
5. *Supplemental revenue*: Guided care generates significant costs for the practice: the nurse's salary and benefits, office space, equipment (i.e., computer, cell phone), communication services (i.e., cell phone service, access to the Internet), and travel costs. To adopt guided care, a practice must be confident that it will receive a supplemental revenue stream that will offset these costs, e.g., risk-adjusted capitation payments.

Steps Toward Implementing the Guided Care Model

Most primary care practices can fully implement guided care in 6–9 months. There are five critical steps in implementing guided care.

1. Preparing the physicians and office staff

   It is important to introduce guided care to the physicians and the practice staff and to describe how it will work in the practice. Staff members should understand that they will need to adjust some established roles and procedures to collaborate effectively with the GCN. Some of the information that should be communicated is described in Table 11.1.

   Physicians are involved in hiring, orienting, and evaluating the nurse, and are responsible for communicating regularly with the nurse about their patients and their teamwork. Table 11.2 provides a summary of the physicians' roles and responsibilities.
2. Identifying patients who are likely to benefit from guided care

   The practice's 20–25 % of patients who have the highest estimated likelihood of incurring high health care cost are identified, usually by analyzing older patients' previous 12 months of health insurance claims with a predictive model, such as the Hierarchical Condition Category [13], which is available in the public domain. Although clinicians are capable of identifying patients with multi-morbidity, electronic predictive models can identify such patients more objectively, consistently, and efficiently.
3. Hiring the nurse

   The next step is to hire a registered nurse who has completed an accredited course in Guided Care Nursing and earned a Certificate in Guided Care Nursing. To attract strong applicants, the practice should offer a salary that is competitive with local hospital and home health care employers. See Table 11.3 for required and desirable qualities of GCN applicants.
4. Integrating the nurse into the practice

   A practice leader is responsible for orienting the nurse to the people and procedures of the practice, and for orienting the physicians and other staff members to the nurse and to the operational details of how guided care will work in the practice. The goals of the orientation are for the nurse to begin to develop effective teamwork with the physicians and staff members, as well as to become familiar with office procedures and health-related resources in the local community.

   To begin building the essential nurse-physician teamwork, it is important that the nurse meet with each physician to define the many processes that they will soon conduct as a team; see Table 11.2. To build teamwork as

Table 11.1 Discussion outline for preparing physicians and office staff

Guided care introduction	Inform staff members that the practice has committed to adopting guided care
	Explain the practice's rationale for adopting guided care
	Acknowledge that change is difficult and slow, but produces benefits in the long run
	Confirm that attendees have received a written description of guided care
Describe how guided care will work in the practice	Discuss how guided care is funded
	Describe plans for hiring the nurse(s), identifying eligible patients, communicating with patients, and equipping office space
	Describe how the practice will orient the nurse and hold meetings of the GCN and the office staff
Questions	Discuss the staff's concerns and questions about guided care

Table 11.2 The physician and GCN roles and responsibilities in guided care

Nurse selection (see Table 11.3)	Each physician with whom the nurse will work should review resumes, conduct interviews, and participate in the ranking of applicants
Nurse orientation	Each physician should meet with the nurse several times during the nurse's orientation to define how they will work together to care for patients. The physicians should also introduce the guided care patients to the nurse during routine office visits and allow the nurse to observe the physician's style of interacting with these patients and their family caregivers
Building the caseload	The physician meets with the nurse for 20–25 min per patient to discuss and revise the preliminary care guide that the nurse creates following the initial home assessment
Updating each other about the status of patients	The GCN provides the physician with a current list of their mutual guided care patients
	The GCN notifies the physician of significant changes in their mutual patients' status, especially changes occurring between office visits and during care in hospitals and skilled nursing facilities
	The physician notifies the nurse of changes in their mutual patients' status, especially admissions to hospitals, visits to emergency departments, and referrals to specialists
	Depending on personal preferences, notifications could occur by e-mail, voice mail, hard copy notes, direct conversations, and/or entries in the medical record
Providing care collaboratively	The GCN and physician discuss and modify the preliminary care guides of patients who enroll in guided care
	The nurse joins the physician in the examining room during office visits, especially with patients who have acute problems or difficulty with communication, cognition, and/or adherence or who have recently received care in hospitals or emergency departments
Quality improvement processes	The GCN and the physician discuss ways to improve their guided care teamwork and the nurse attends appropriate office staff meetings

Table 11.3 Required and desirable qualities of GCN applicants

The minimum requirements for people who apply for the GCN position are:
• Current licensure as a registered nurse
• Completion of an accredited, online course in Guided Care Nursing. For information on the course, please visit https://www.ijhn-education.org/content/guided-care-nursing
• A Certificate in Guided Care Nursing. To earn the certificate, a nurse must successfully complete the Guided Care Nursing online course. The certificate could be earned between a nurse's hiring and starting to work in a guided care practice
• A minimum of 3 years of nursing experience, preferably with older patients
• Skill in using computers, the Internet, and health information technology
• Ability to travel frequently to hospitals, skilled nursing facilities, patients' homes, and other sites where patients receive care (as indicated by patients' needs)
Other desirable qualities include:
• Excellent interpersonal skills
• Flexible and creative problem-solving skills
• Good clinical judgment and decision-making skills
• Demonstrated ability to work independently and as a member of an interdisciplinary team
• Clear understanding of the role of a GCN
• Desire to learn and practice all of the position's components
• Commitment to "coaching" (rather than "teaching") patients to improve their health behaviors to attain their health-related goals
• Commitment to learning about and referring patients to health-related services in the local community
• Effective skills in oral and written communication, listening, and assertion

a new member of the office staff, the nurse meets with each office staff member to learn each person's role and the administrative relationships among them.

5. Managing guided care

   The success of guided care depends heavily on the physicians' cooperation with the GCN and the GCN's consistent performance of certain essential activities. To ensure consistent performance of essential activities, the practice should participate in a system of continuous quality improvement. The GCN's supervisor should provide the GCN with a list of essential guided care activities, a performance goal for each activity, a description of how the nurse should document each activity, and a schedule of quarterly feedback and evaluation meetings. The supervisor should then manage the ongoing processes of guided care, attending watchfully to the GCN's rates of completion of monthly patient monitoring calls and visitation of hospitalized patients, both in the hospital and at home shortly after discharge. Periodic surveys to ascertain patients,' caregivers', and physicians' perceptions of the quality of care can also be used to ensure that guided care is producing the desired effects on chronic care.

Technical Assistance in Adopting Guided Care

Several forms of technical assistance are available [14] to practices that wish to adopt the guided care model.

- An implementation manual titled *Guided Care*: *A New Nurse-Physician Partnership in Chronic Care* provides many tools, resources, and lessons learned for adopting guided care [15].
- An accredited, online course in Guided Care Nursing is a 6-week, 40-h Web-based course and examination that lead to a Certificate in Guided Care Nursing.
- An accredited, asynchronous, online, CME-eligible, nine-module course provides physicians, practice administrators, and other practice leaders with an awareness of the competencies that facilitate effective practice within all types of medical homes.

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References

1. Counsell SR, Callahan CM, Tu W, Stump TE, Arling GW. Cost analysis of the geriatric resources for assessment and care of elders care management intervention. J Am Geriatr Soc. 2009;57(8):1420–6. Epub 2009/08/20.
2. Reid RJ, Coleman K, Johnson EA, Fishman PA, Hsu C, Soman MP, et al. The Group Health medical home at year two: cost savings, higher patient satisfaction, and less burnout for providers. Health Aff. 2010;29(5):835–43. Epub 2010/05/05.
3. Wennberg DE, Marr A, Lang L, O'Malley S, Bennett G. A randomized trial of a telephone care-management strategy. N Engl J Med. 2010;363(13):1245–55. Epub 2010/09/24.
4. Boult C, Green A, Boult L, Pacala J, Snyder C, Leff B. Successful models of comprehensive care for older adults with chronic conditions: evidence for the Institute of Medicine's "retooling for an aging America" report. J Am Geriatr Soc. 2009;57(12):2328–37. Epub 2010/02/04.
5. Peikes D, Chen A, Schore J, Brown R. Effects of care coordination on hospitalization, quality of care, and health care expenditures among Medicare beneficiaries: 15 randomized trials. JAMA. 2009;301(6):603–18. Epub 2009/02/13.
6. Wagner E. Chronic disease management: what will it take to improve care for chronic illness? Eff Clin Pract. 1998; 1(1):2–4.
7. Boyd C, Boult C, Shadmi E, Leff B, Brager R, Dunbar L, et al. Guided care for multi-morbid older adults. Gerontologist. 2007;47(5):697–704.
8. Wolff J, Rand-Giovanetti E, Palmer S, Wegener S, Reider L, Frey K, et al. Caregiving and chronic care: the guided care program for families and friends. J Gerontol A Biol Sci Med Sci. 2009;64(7):785–91.
9. Boult C, Leff B, Boyd CM, Wolff JL, Marsteller JA, Frick KD, et al. A matched-pair cluster-randomized trial of guided care for high-risk older patients. J Gen Intern Med. 2013;28(5):612–21. Epub 2013/01/12.
10. Boult C, Reider L, Frey K, Leff B, Boyd C, Wolff J, et al. Early effects of "Guided Care" on the quality of health care for multimorbid older persons: a cluster-randomized controlled trial. J Gerontol A Biol Sci Med Sci. 2008;63A(3):321–7.
11. Marsteller JA, Hsu YJ, Wen M, Wolff J, Frick K, Reider L, et al. Effects of guided care on providers' satisfaction with care: a three-year matched-pair cluster-randomized trial. Population health management. 2013. Epub 2013/04/09.
12. Wolff J, Giovannetti E, Boyd C, Reider L, Palmer S, Scharfstein D, et al. Effects of guided care on family caregivers. Gerontologist. 2010;50(4):459–70. Epub 2009/08/28.
13. Pope G, Kautter J, Ellis R, Ash A, Ayanian J, Lezzoni L, et al. Risk adjustment of medicare capitation payments using the CMS-HCC model. Health Care Financ Rev. 2004;25(4):119–41.
14. MedHomeInfo. Baltimore, MD: Johns Hopkins University. 2009. http://www.medhomeinfo.org/ (2009). Accessed 10 Aug 2014.
15. Boult C, Giddens J, Frey K, Reider L, Novak T. Guided care: a new nurse-physician partnership in chronic care. New York, NY: Springer Publishing Company; 2009.