

Optimizing Patient and Family Involvement in Geriatric Home Care

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Abstract: Although a growing body of literature supports the expansion of patient and family involvement in healthcare processes, little attention has thus far been directed at activating geriatric home care patients and/or families to be more effective in managing health-related activities. In this manuscript we consider the unique needs, attributes, and circumstances of the geriatric home care population in conjunction with patient, family, provider, and organizational interventions with a primary or secondary objective of activating patients and/or families. We summarize what has been learned from these efforts, with attention to feasibility and potential applicability to geriatric home care.

Keywords
chronic care
home healthcare
patient activation

An emerging vision of high-quality chronic and geriatric care embraces a fundamental shift in the balance of patient-provider relationships toward comprehensive information exchange, collaboration, and shared decision making. (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Reuben, 2007). This paradigm demands that patients' preferences and goals be solicited and respected by healthcare providers and recognizes that patients' efforts largely determine the success of chronic care processes and outcomes. This emerging vision explicitly places patients at the center of healthcare processes, and dictates a shift in the orientation of how providers interact with patients. It suggests that providers must not only address patients' health needs, preferences, and values, but also account for varied patient strengths, skills, and capacity so as to provide appropriate information and resources that facilitate shared decision making and self-care management. The purpose of this paper is to summarize the evidence base regarding patient, family, provider, and health system characteristics that impede or facilitate productive involvement of patients and their families. Our goal is to inform efforts that optimize patient and family involvement in geriatric home care processes, and in doing so, to advance the quality of geriatric home care.

Patient and Family Involvement in Geriatric Home Care

Conceptual Orientation

Home care is just one facet of healthcare provision for individuals with chronic illness. Key features of the environment (home, neighbor-

hood, community, accessibility of healthcare providers, community service systems) also influence the scope and nature of patient and family involvement in healthcare decision making and delivery. The following discussion focuses on factors directly pertinent to patient, family, and provider interactions that represent opportunities for intervention and improvement of home care processes and outcomes. Home care processes encompass both the provision of medical services and interpersonal interactions that include the exchange of information, ideas, skills, and emotional support among patients, families, and home care providers. Interpersonal interactions, influenced by individuals' expectations, personalities, health beliefs, cultures, and other personal attributes, may facilitate or impede the productivity of home care and the extent to which patients and their families are "activated" to assume healthcare management tasks. "Activation" is broadly defined as the attributes and skills required by patients and families to be effectively involved in care (Hibbard, Stockard, Mahoney, & Tusler, 2004). Outcomes are both "proximal" (e.g., health behaviors) and "distal" (e.g., safety, efficacy, efficiency, patient-centeredness, etc.).

In this paper, we examine patient, family, and provider characteristics that are salient to the quality and outcomes of geriatric home care processes. We then turn our attention to patient, family, provider, and organizational interventions that have been developed with a primary or secondary objective of activating patients and/or families. We discuss implications for home care providers with attention to feasibility and potential applicability to geriatric home care, and recommend additional research to address knowledge gaps.

Patients

Patient characteristics are relevant to the roles and responsibilities patients and their families assume in home care, as well as the specific strategies best suited to optimize their involvement. Various concepts, definitions, and measures have been used to describe factors affecting patients' involvement in healthcare;

here we distinguish between two types of attributes that have a bearing on how to effectively engage patients in their healthcare. We describe relatively static characteristics such as cognition, healthcare literacy, sensory functioning, and English proficiency that may require accommodation or compensation by providers. We contrast these with more readily modifiable factors such as confidence, efficacy, and motivation, which have been shown to respond to capacity-building interventions designed to enhance patient participation (Table 1; Greenfield, Kaplan, & Ware, 1985; Greenfield, Kaplan, Ware, Yano, & Frank, 1988; Kinnersley et al., 2007; Lorig et al., 1999).

Compensatory approaches, shown in the top panel of Table 1, refer to targeted strategies or efforts that may be undertaken by home care providers to accommodate deficits in patients' capabilities. For example, patients with low education or healthcare literacy typically ask fewer questions, are less likely to request addi-

tional services, and are less apt to seek new information (Gazmararian, Williams, Peel, & Baker, 2003; Katz, Jacobson, Veledar, & Kripalani, 2007; Street, Gordon, Ward, Krupat, & Kravitz, 2005). By using partnership-building and supportive communication (e.g., slowing the speed of speech, using less complex words, prompting patients to ask questions or restate information or instructions) (Roter, Erby, Larson, & Ellington, 2007; Schillinger et al., 2003; Street et al., 2005), or making available targeted resources such as large-print materials, simple language, or educational aides (Dohan & Schrag, 2005), home care providers may be able to diminish the negative consequences of low healthcare literacy on patients' comprehension and knowledge. These compensatory efforts seek to bridge the gap between health system demands and individual capacity, and depend on healthcare provider actions.

Table 1. Salient Patient Attributes for Health Care Decision-Making, Problem Solving, and Management

Construct	Definition	Strategies
Static Attributes: Potential for Compensation or Accommodation		
Cognition	Mental processes involved in gaining knowledge and comprehension, including thinking, knowing, remembering, judging, and problem solving	Involving family in health care processes, use of simple language and graphics
Vision and Hearing	Sensory functioning that is influential to the exchange of health care information	Large print materials, slowing the rate and using louder speech
English Proficiency	Ability to read, write, speak in English, compute and solve problems to achieve one's goals, develop one's knowledge and potential	Simple language, use of graphics and pictures, translation of information to other languages
Health Literacy	Functional and context-specific oral (listening; speaking) and written (reading; writing) skills	Simple language, use of graphics and pictures, slowing the rate of speech, use of simple language, prompting patients to ask questions or restate information
More Modifiable Factors: Potential for Capacity Building		
Self efficacy; Personal Mastery	Belief in one's capabilities to organize and execute the courses of actions required to produce given attainments; behavior specific	Pre-visit education and coaching using written materials, videos, audiotapes, and/or face-to-face sessions to encourage patients to be more proactive and engaged within a health care encounter by prompting them to ask questions, raise concerns, request clarification, or negotiate decisions; Self management programs that rely on education and problem solving
Internal Locus of Control	Individual's perceived internal control; sense of responsibility for health outcomes	
Readiness to Change Health Behaviors	Behavior change as an individual process based on decisional balance (benefits and costs), self-efficacy, and temptation	
Patient Activation	Knowledge, skills, beliefs, behaviors needed to self manage health care	

A range of modifiable attributes such as self-efficacy, internal locus of control, readiness to change health behaviors, and patient activation relate to patients' confidence, motivation, and ability to execute a set of actions, are also relevant to healthcare decision making, problem-solving, and management activities (bottom panel of Table 1). Although we acknowledge subtle differences in these constructs, for the sake of simplicity and that of interventions seeking to address these factors are similar in approach, we rely on the term "patient activation" to collectively describe these constructs. Patient activation has been defined as "the broad range of attributes and skills required by patients to effectively self manage their healthcare" (Hibbard et al., 2004) and has been shown to independently influence information-processing and decision making, particularly among individuals with low literacy (Hibbard, Peters, Dixon, & Tusler, 2007). Further, previous research suggests that patients' confidence, motivation, and skills ("activation") to manage healthcare activities are amenable to capacity-building intervention (Greenfield et al., 1985, 1988; Kinnersley et al., 2007; Lorig et al., 1999). For example, patients may be coached or prompted to assume a more proactive and engaged role within medical care encounters (Greenfield et al., 1985, 1988; Kinnersley et al., 2007) and may be taught to more effectively manage health activities (Lorig & Holman, 2003; Lorig et al., 1999). Interventions seeking to improve patient activation are designed to prepare patients for independent action—in short, to help patients help themselves.

Families

Patients often choose to include family members in treatment decisions (Deimling, Smerglia, & Barresi, 1990; Ende, Kazis, Ash, & Moskowitz, 1989; Kapp, 1991), particularly patients who are older, sicker, and faced with difficult decisions (Eggly et al., 2006; Ende et al., 1989; Ishikawa, Roter, Yamazaki, & Takayama, 2005). Implications of subtle nuances in the behaviors assumed by family in facilitating information exchange and activating patient engagement in healthcare processes are only beginning to be understood, and have not been examined thus far within the context of home care. The presence of a companion within a physician office visit has been found to generally benefit communication (Brown, Brett, Stewart, & Marshall, 1998; Clayman,

Roter, Wissow, & Bandeen-Roche, 2005; Ishikawa et al., 2005; Prohaska & Glasser, 1996; Schilling et al., 2002; Wolff & Roter, 2008) and to be associated with patient question asking and information sharing (Eggly et al., 2006; Labrecque, Blanchard, Ruckdeschel, & Blanchard, 1991; Schilling et al., 2002). One study of audiotaped physician visits among accompanied older adults found that patients whose companions prompted their involvement (e.g., by asking the patient questions or their opinion, prompting them to talk) were 4.5 times more likely to be involved in decision making than their counterparts (Clayman et al., 2005). Although not well delineated, it is likely that family characteristics such as literacy, stress, confidence, and expectations are salient to both patient and family engagement in healthcare processes, as well as outcomes related to those processes.

Through both choice and necessity, families are typically highly involved in geriatric home health patients' care, but providers may fail to recognize their informational needs and involvement in managing, monitoring, and providing care (Driscoll, 2000; vom Eigen, Walker, Edgman-Levitan, Cleary, & Delbanco, 1999; Weaver, Perloff, & Waters, 1998). Information provision has been favorably related to family perceptions of post-discharge preparedness (Bull, Hansen, & Gross, 2000; Weaver et al., 1998) and to fewer subsequent medical problems among discharged patients (Driscoll, 2000). One study found that providers' recognition, respect, and agreement with families' goals for patient care was favorably associated with families' perceived preparedness for managing patients' post-hospital care, as well as patients' post-discharge symptoms and functioning (Weinberg, Lusenhop, Gittell, & Kautz, 2007). Overall, the evidence indicates that involvement of families as partners in acute and post-acute care benefits patients.

Patient-centered care has been widely used to describe a healthcare model that emphasizes the central role of patients in healthcare processes. Relationship-centered care (RCC) has been recently offered as a related, but broader paradigm. RCC also emphasizes the importance of patients' needs and preferences, but affirms that patients are embedded within a web of interpersonal relationships that are not only influential, but central in healthcare decision making, management, recovery, and outcomes across time and settings of care

(Beach & Inui, 2006). This reframing is particularly salient to home care, where providers interface with patients in their home and community, and families are highly involved in the provision of assistance. This reframing of perspective shifts the intended target of activities from the “patient” and/or “the patients’ family” to the patient within the context of their social and helping relationships, and suggests that patient activation efforts are most effective when they incorporate and capitalize on the presence of family members who are involved in patient care. Likewise, the perspective dictates that family members cannot be activated without the cooperation and consent of patients themselves.

Home Care Providers

Although the dynamics of home care patient-provider communication has not been systematically examined, studies of patient-physician communication provide some relevant insights. This research indicates that physicians tend to be more task-oriented (Hall, Milburn, Roter, & Daltroy, 1998; Hall, Roter, Milburn, & Daltroy, 1996; Kaplan, Greenfield, & Ware, 1989), engage in less social dialogue (Hall, Epstein, DeCiantis, & McNeil, 1993; Hall, Horgan, Stein, & Roter, 2002; Hall et al., 1996), and solicit less information from their sickest patients (Bradlock, Edwards, Hasenberg, Laidley, & Levinson, 1999; Marvel, Epstein, Flowers, & Beckman, 1999). Given that the health status of geriatric home care populations is significantly compromised, this research suggests that developing approaches to promote collaborative interactions may be especially challenging and require targeted competencies and skills among home health professionals.

Interpersonal Home Care Processes

Several interrelated dimensions of patient-family-provider exchanges are relevant to whether interpersonal home care processes facilitate or impede patients’ and families’ motivation and confidence to assume health-care management tasks. Rapport of medical dialogue, provision of knowledge, skills, services, procedures, coordination of care, and degree of shared decision making have all been shown to influence patient and family involvement in other types and settings of care (Kaplan et al., 1989; Roter & Hall, 2006a; Stewart, 1995). Thus it is likely they are important in home care as well.

Outcomes

Patient and family involvement in geriatric home care processes are salient to a number of important outcomes. For example, as described in Table 2, aspects of interpersonal healthcare processes influence the extent to which patients and families manage medical treatments (e.g., take medications, adhere to diet or exercise regimens, monitor health), develop or maintain meaningful social roles, and cope with emotional issues emanating from their health conditions. As a corollary, patient activation also has been shown to influence self-management behaviors (Hibbard, Mahoney, Stock, & Tusler, 2007; Hibbard, Mahoney, Stockard, & Tusler, 2005; Hibbard et al., 2004; Mosen et al., 2007). Self-management in turn has been shown to influence satisfaction with care (Mosen et al., 2007), health services use and costs (Sokol, McGuigan, Verbrugge, & Epstein, 2005) as well as physiologic measures of health status (DiMatteo, Giordani, Lepper, & Croghan, 2002; Lorig, Ritter, Laurent, & Plant, 2006).

Opportunities to Improve Patient and Family Involvement in Geriatric Home Care

A number of patient, family, provider, and organizational interventions have been tested with a primary or secondary objective of activating patients and/or families to be more effective in managing healthcare activities. Here we summarize what has been learned from these efforts, with attention to their feasibility and potential applicability in geriatric home care.

Patients

Perhaps the most widely disseminated intervention to promote patient activation in healthcare processes is Stanford’s chronic disease self-management program (CDSM). The community-based program, comprising six weekly 2.5-hr sessions, is facilitated by trained peer leaders and focuses on goal setting, coping, and problem-solving skills related to managing emotions, symptoms, and health-related tasks as well as communicating with family, friends, and healthcare providers. In the original trial, intervention group participants reported improvements in self-efficacy, health behaviors, and health status, as well as lower healthcare utilization at 6 months follow-up (Lorig et al., 1999). Although the CDSM

Table 2. Dimensions of Interpersonal Home Care Processes

Construct	Definition
Rapport of Medical Dialogue	Whether patients, families, and providers are comfortable with one another and feel trusted, respected, valued, and supported is influential to information sharing, ^{a,b} patients' satisfaction with care, ^c as well as health outcomes such as symptom resolution, emotional well-being, physical functioning, and physiologic measures ^{d,e,f}
Provision of Knowledge, Skills, Services, Procedures, Coordination of Care	Refers to skill development and whether knowledge and skills are effectively communicated in a manner that is understandable to patients and families and that facilitates confidence and proficiency in tasks they are expected to assume; A set of actions designed to ensure the coordination and continuity of care as patients transfer between different locations or levels of care within the same location. ^g Is thought to encompass information transfer, patient and family preparation, self-management support, and patient empowerment to assert preferences ^h
Shared Decision-Making	The extent to which patients are offered choices, asked their opinions, and share in decision making is an indicator of the preeminent bioethical principle of patient autonomy. Although attributes may vary across decision complexity, degree of certainty, and ramifications of alternatives, the clinical issues to be addressed should be defined and explained in an understandable manner, and options discussed in sufficient detail so that patients may assess them within the context of their own preferences and values system

Note.

^aSchmid Mast, M., Hall, J., & Roter, D. (2008). Caring and dominance affect participants' perceptions and behaviors during a virtual medical visit. *J Gen Intern Med.* 23(5), 523–527.

^bBeach, M., Roter, D., Wang, N., Duggan, P., & Cooper, L. (2006). Are physicians' attitudes of respect accurately perceived by patients and associated with more positive communication behaviors? *Patient Educ Couns.* 62(3), 347–354.

^cJackson, J., Chamberlin, J., & Kroenke, K. (Feb 2001). Predictors of patient satisfaction. *Soc Sci Med.* 52(4), 609–620.

^dStewart, M. (May 1 1995). Effective physician–patient communication and health outcomes: A review. *CMAJ.* 152(9), 1423–1433.

^eRoter, D., & Hall, J. (2006). Consequences of Talk: The Relationship of Talk to Outcomes. In *Doctors talking with patients/patients talking with doctors: improving communication in medical visits*. 2nd edition (pp. 143–164). Westport, CT: Praeger Paperback/Greenwood Publishing Group, Inc.

^fKaplan, S., Greenfield, S., & Ware, J., Jr. (Mar 1989). Assessing the effects of physician–patient interactions on the outcomes of chronic disease. *Med Care.* 27(3 Suppl), S110–S127.

^gColeman, E., & Boult, C. (Apr 2003). Improving the quality of transitional care for persons with complex care needs. *J Am Geriatr Soc.* 51(4), 556–557.

^hColeman, E., Mahoney, E., & Parry, C. (Mar 2005). Assessing the quality of preparation for posthospital care from the patient's perspective: the care transitions measure. *Med Care.* 43(3), 246–255.

approach is widely accepted, meta-analyses of randomized trials of self management programs find variability in conceptual orientation, methodological rigor, method of delivery, intensity, duration, and inconsistency in findings both across and within diseases (Chodosh et al., 2005; Newman, Steed, & Mulligan, 2004; Warsi, Wang, LaValley, Avorn, & Solomon, 2004). Uncertainty as to the active ingredient or mechanism by which these interventions are effective, limits identification of the most essential components for inclusion in geriatric home care programs. Further, the CDSM's current reliance on face to face peer

interaction or internet communication (Lorig et al., 2006) is problematic for the frail elderly, homebound population with limited computer access.

Another relevant approach to home care is educational and/or coaching interventions that seek to increase patient involvement in medical encounters. These interventions rely on written materials, videos, audiotapes, face-to-face sessions, or a combination of techniques, and are typically delivered immediately before a patient's healthcare encounter (Griffin et al., 2004; Harrington, Noble, & Newman, 2004; Kinnersley et al., 2007). This approach is

designed to help patients address their information needs by encouraging them to raise concerns, request clarification, ask questions, and negotiate medical decisions with their providers. A Cochrane review concluded that coaching approaches may result in small increases in patient question asking, visit satisfaction, and possibly lower anxiety; however, there was inconclusive evidence of change in patient knowledge (Kinnersley et al., 2007).

Families

Activating interventions for families of geriatric home care patients may be directed to improving either the supportive role that families play in coaching patients' involvement in healthcare processes or the direct role that families assume in providing hands on healthcare assistance, such as medication management. We are unaware of interventions that have been developed to explicitly improve families' support in coaching patient involvement within home healthcare processes. However, there is substantial evidence of incongruence between patients' and families' expectations as to the role of family members in healthcare processes (Glasser, Prohaska, & Gravidal, 2001; Ishikawa, Roter, Yamazaki, Hashimoto, & Yano, 2006; Ishikawa et al., 2005)—for example, accompanying companions may intend to assume a more extensive role in visit communication than expected or desired by patients. These findings suggest that training families to coach and support geriatric home care patients would have potentially important benefits for patients.

Numerous interventions have been developed for family caregivers of chronic or acutely ill or disabled older adults. Meta analyses find positive, albeit small effects for outcomes, most notably depression, strain, and burden (Mason et al., 2007; Sorensen, Pinguart, & Duberstein, 2002; Zarit, Gaugler, & Jarrott, 1999). Family caregivers' perceived preparedness to provide health-related assistance appears to be amenable to improvement through interventions (Pinguart & Sorensen, 2006; Sorensen et al., 2002). Interventions that are more comprehensive, individually tailored, and that actively engage both caregivers and recipients with a combination of education, skills, and coping techniques appear to be most effective (Gallagher-Thompson & Coon, 2007; Schulz,

Martire, & Klinger, 2005; Sorensen et al., 2002).

Providers

Provider-focused approaches to activate patients and families generally seek to improve clinicians' communication and patient-education skills. We did not locate research on communication interventions targeted specifically to home care providers. However, numerous communication interventions with physicians show some success and are potentially relevant to the home care context (Griffin et al., 2004; Roter & Hall, 2006b). Strategies to increase patient participation in medical encounters focus on improving providers' skills in prompting patient question asking and use of collaborative communication techniques that confirm patient knowledge and understanding.

Organizational Interventions

A number of approaches to improve care coordination and/or transitional care for older adults have been tested. Typically these approaches have involved introducing a new healthcare professional to the care team who has specific responsibilities to collaborate with and support and educate patients and families. Some interventions have proven successful (Wolff & Boulton, 2005), and suggest that the redesign of the healthcare team may effectively engage patients and families and result in improved home healthcare processes and outcomes. However, organizational interventions are complex, differ from one another, and operate through a variety of mechanisms. Most importantly, the extent to which organizational redesign enhances patient activation has not typically been examined or reported. Geriatric home care could provide an opportunity to test organizational strategies, and this approach may prove to be effective given the complexity and expense of managing older people with chronic illness and disability in the home.

Obstacles to Implementation in Practice

Given the limited diffusion of many successful health system innovations (Wolff & Boulton, 2005), attention to the potential obstacles in dissemination of patient and family activation merits careful attention. Currently, there is an absence of infrastructure to support activation activities. Reimbursement systems do not

permit time spent in education or the potentially intensive discussions required for adequate information exchange, shared decision making, and patient and family educational activities, particularly as it concerns family involvement and training. Effective interactions with patients who are less literate or who face difficult treatment decisions may require more treatment sessions and clinical attention than presently feasible. Home care providers may perceive family involvement as too challenging or time consuming. Lastly, the diversity of geriatric home care patients' clinical needs, abilities, preferences, and social context challenges a single structured approach. Instead, what is required is a more tailored approach, one in which home care processes are targeted to the specific needs and abilities of patients and families.

Vision for the Future and Recommendations

The centrality of patient and family involvement to geriatric home care processes and the complexity of factors that promote or impede care dynamics are evident from this overview of the literature. Despite a body of knowledge supporting the involvement of patients and families in their healthcare, little attention has thus far been directed to the geriatric home care context. With the increasing emphasis on providing care at home and rising importance of geriatric home care, attention to this aspect of home care is critical. Here we summarize some of the most promising approaches to optimize patient and family efforts given the unique needs and attributes of this population. Three points emerge as particularly notable:

1. Purposeful efforts to promote patient and family involvement in geriatric home care should be incorporated into clinical practice and research. Obstacles posed by patient cognition, healthcare literacy, and/or language should be recognized and accommodated with supplemental or customized resources. Capacity-building approaches that activate patients and families to more effectively manage healthcare activities have been shown to be successful, but have not been specifically examined within the context of home care. Both approaches merit consideration and further research to determine best practices within geriatric home care. A related point is that patient/family activation will require the training of health professionals and the development of new competencies and skills relevant to this aspect of home care.
2. The notion of patient-centered care should be revisited. Attention should be given to the potential inefficiencies of separating efforts to activate patients in the absence of involved families, or conversely, intervening with caregivers in the absence of supporting the patients they assist. Partnership-building efforts between patients and families might jointly develop skills, promote collaboration, and simultaneously activate both members of the dyad or family unit. Further research is necessary to evaluate the relative merits of these different approaches for patients, families, and quality of care. Interventions to support family caregivers' provision of care should be distinguished from those designed to enhance their involvement in geriatric home care processes. Consideration should be given to the development of both a "family activation" measure to ascertain families' proficiency, motivation, and confidence to engage in managing patients' healthcare activities, as well as an instrument to assess patients' preferences for family involvement in healthcare processes and decision making.
3. Geriatric home care patients interact with a range of primary and specialty physicians, nurses, pharmacists, physical and/or occupational therapists, and institutional providers such as hospitals or skilled nursing facilities as they transition through a single acute episode of care. Increasing the capacity of geriatric home care patients and their families to participate in home care processes in isolation from other healthcare providers is a potentially useful first step, but is unlikely to be maximally effective. Efforts to engage patients and their families in transitional care processes are promising (Coleman, Parry, Chalmers, & Min, 2006; Naylor et al., 1999, 2004) and should be expanded to include home healthcare.

More broadly, the research base in this area is sparse and inconsistent and would benefit from interdisciplinary collaboration, attention to measurement issues, and more in-depth un-

derstanding of the most effective and feasible strategies for enhancing patient and family involvement on current home care practices and policy.

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