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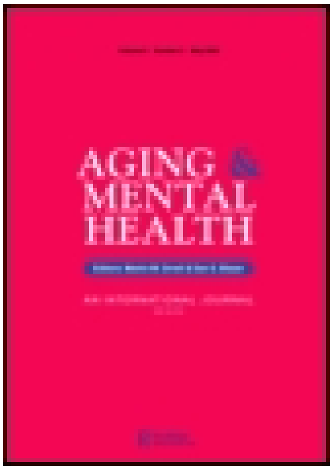

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Health care triads and dementia care: Integrative framework and future directions

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Health care triads and dementia care: integrative framework and future directions

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Abstract
Physicians are usually the first contact in the health care system for persons with dementia and their family caregivers. This paper provides a synopsis of research findings and knowledge gaps regarding interactions among these participants in the health care triad—primary care physicians, family caregivers, and persons with dementia. Research traditions that inform knowledge about health care triads and dementia care include: older patient–physician relationships; the stress-coping social-support health model that dominates family caregiver research; the social learning-self-efficacy model; and literature on the quality of medical care. An integrative framework is presented to illustrate how the quality of interaction in dementia care encounters may be influenced by specific characteristics of members of the health care triad. Domains of dementia care interaction include symptom diagnosis, symptom management, medication management, support service linkage, and emotional support. The integrative framework also links the quality of interaction in these domains with health-related outcomes relevant to each of the health care triad members. Most empirical research in this area has found that family caregivers are dissatisfied with many aspects of physicians' dementia care, but measurement techniques vary widely and little is known about how the quality of physician care is associated with health-related outcomes. Physician surveys have shown that they are least certain about the quality of support service linkage advice they provide. Virtually no research has examined how the person with dementia experiences medical care encounters with physicians and their family members. Much remains to be learned about the longitudinal experience of each member of the health care triad, and how the quality of dementia care encounters changes over the course of the disease process. In this era of rapidly expanding educational and support service interventions for persons with dementia and their family caregivers, as well as computer-based information about dementia care, the influence of these external factors on health care triad interactions and outcomes also remains to be studied.

Introduction

The last two decades of the 20th century witnessed an explosion of empirical research documenting the extent and consequences of family involvement in the daily care of older relatives with a wide variety of chronic illnesses. Health policy makers often hail family care for chronically ill relatives as a virtue of our society. However, social and behavioral scientists have repeatedly found that family caregivers often experience serious emotional and physical health problems due to the demands of ongoing care responsibilities (Schulz *et al.*, 1990; Schulz *et al.*, 1997; Shaw *et al.*, 1997). Higher rates of mortality have been found among highly strained elderly spouse caregivers, compared to non-care-giving spouse controls (Schulz & Beach, 1999). Family members caring for older relatives with Alzheimer's disease and other types of dementia have been found to be at greater risk for adverse health-related outcomes compared to family caregivers of older adults with other health problems (Ory *et al.*, 1999).

For most family caregivers of persons with dementia, physicians are the first and only contact in the health care system, both before and at the time a differential diagnosis of Alzheimer's disease or other cause of dementia is made (Heagerty & Eskenazi, 1994; Silliman, 1989). From a health care system perspective, physicians are in a unique position to help family caregivers reduce the risks of adverse outcomes by carefully explaining the dementia disease process, advising how to manage symptoms as they occur, and linking caregivers with appropriate community support services (Maslow, 1990). In the early 1990s, the American Medical Association (AMA) officially recognized the pivotal role primary care physicians could play in helping alleviate the adverse effects of family care-giving. The AMA called for health care partnerships between family caregivers and primary care physicians, and recommended medical education and health care reimbursement initiatives to encourage physicians to use the partnership model (Council on Scientific Affairs, 1993).

Ironically, this recent rush to couple family caregivers and physicians runs its own risk of marginalizing the patient, or the person with

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dementia. People with dementia progressively lose cognitive function as the disease process advances over time, and historically have been seen by most clinicians and social and behavioral scientists "…as incidental subjects and passive recipients in the process of their dementia" (Keady & Gilliard, 1999). This perception of people with dementia as non-participants in their own care decisions is rapidly changing, however, as increased public awareness of Alzheimer's disease and other types of dementia leads to medical intervention and diagnostic testing earlier in the disease process. As people with dementia engage in the care process, it will be increasingly important to understand how they interacted with both family caregivers and physicians before their dementia, and how they interact during medical encounters.

The major purpose of this paper is to provide a synopsis of research issues and questions regarding the interactions of people with dementia, their family caregivers, and the medical care system, including primary care physicians. To achieve this purpose in a conceptually coherent fashion, the concept of "health care triad" is used to depict the person with dementia, the family caregiver, and the primary care physician. Interactions between family caregivers and other health or social service providers are not considered part of the health care triad for purposes of this paper, however, these interactions may influence, or be affected by, interactions with physicians. To further simplify the discussion, only a "primary" family caregiver is assumed in the health care triad, even though multiple family caregivers may be involved in physician interactions. An integrative framework is presented that places critical dementia care issues within the context of health care triad members' characteristics and the purposes of their interactions.

An explicit goal of this paper is to help link social and behavioral science approaches to the study of dementia care issues with the needs and realities of clinical practice and public policy development. Therefore, the proposed integrative framework incorporates health-related outcomes that are theoretically expected to result from interactions in dementia care triads, but that also are relevant to health care practitioners and policy makers concerned with improving dementia care. With this background in mind, the major objectives of this paper are to:

- Present and discuss an integrative framework designed to improve understanding of dementia care in the context of health care triads;
- Review research traditions related to the integrative framework;
- Summarize the knowledge base regarding family caregiver–physician/medical care system interactions in the context of dementia diagnosis and management;
- Recommend future research directions and important unanswered questions to inform and improve dementia care practices and policies.

Framework to investigate dementia care in health care triads

Presentation of the model

The model presented in Figure 1 represents an integrated framework designed to highlight the three-way, or triadic, nature of encounters and interaction regarding dementia care in the ambulatory care setting. For simplicity, the physician is assumed to be the primary care physician of the person with dementia. This framework integrates and expands elements from conceptual models of medical encounters between older patients and their physicians offered by others (Beisecker & Beisecker, 1996; Haug 1996), with elements from the conceptual model of Alzheimer's caregiver stress articulated by Pearlin and colleagues (1990), and later elaborated by Aneshensel and colleagues in the context of the care-giving career (1995).

The underlying rationale of this model is that all three members of the health care triad bring socio-demographic, psychological, cultural, and health-related characteristics to the encounter (Beisecker & Beisecker, 1996; Haug, 1996). Any of these factors may influence the success, or quality, of the triadic encounter, although their measurable effects have not been tested in empirical research. Moreover, characteristics of the broader "health care system" are shown as influential, and may be viewed as "environmental" factors as discussed by Andersen (1995) in his widely used behavioral model of health services utilization. For example, the triadic encounter may occur in a managed care organization, or the person with dementia may be insured through a Medicare managed care plan. If additional physicians have been involved (e.g., specialists for the person with dementia), this factor may affect the triadic encounter. Finally, multidisciplinary geriatric team care continues to evolve as a model of comprehensive treatment for frail older adults in a range of health care settings (Boult *et al.*, 1995). The extent to which other health care professionals—especially nurses and social workers—assist primary care physicians with dementia patients in the ambulatory care setting may also influence the content of triadic encounters.

As noted above, family caregivers and their relatives do not interact with physicians and the health care system in a vacuum. Instead, caregivers are "embedded in a wider set of relationships" with other family members and possibly organized sources of dementia care information (Lieberman & Fisher, 1999; Morgan & Zhao, 1993). Given the growth of dementia-specific community support services for patients and family caregivers, including single-site creative interventions, it is increasingly likely that family members will encounter physicians while participating in non-medical educational and support service programs (Bourgeois *et al*., 1996; Ostwald *et al*., 1999). All of these factors may also directly affect health-related outcomes in the model, regardless of what occurs in encounters with physicians or the broader health care system.

The "triadic encounter" is organized into domains that represent the purposes of the encounter, with specific reference to dementia care issues shown in the literature to be important to family caregivers (Beisecker *et al*., 1997; Fortinsky & Hathaway, 1990; Glasser and Miller, 1998; Malone Beach *et al*., 1992; Silliman, 2000). These domains include: diagnosis of dementia-related symptoms; non-pharmacological dementia symptom management before and after diagnosis; medication management for dementia symptoms and co-morbidities; community support service linkage; and emotional support to family caregivers.

The quality of interaction in these domains during encounters is expected to influence health-related outcomes of family caregivers, persons with dementia, and primary care physicians. As Figure 1 indicates, some health-related outcomes pertain more immediately to the purposes of the triadic encounter (e.g., satisfaction with medical care; improved family caregiver self-efficacy in specific domains). Other outcomes reflect longer-term consequences of medical encounters, such as stability of medical co-morbidities and behavior problems in the person with dementia, caregiver's health and well-being, and knowledge and use of community support services by physicians. Short- and long-term outcomes have been discussed by other investigators as benefits to patients as a result of older patient–physician communication (Stewart *et al*., 2000).

Special dementia care considerations

The proposed integrative framework illustrated in Figure 1 must be supplemented with several important considerations specific to the person with dementia that have not been adequately addressed by researchers, clinicians, or policy makers to date. These considerations help shed light on future research directions and important unanswered questions that, if addressed, could improve the process and outcomes of interactions between persons with dementia, family caregivers, and physicians.

First, there is growing empirical evidence that persons with dementia retain a strong sense of self despite cognitive impairment, even though this sense diminishes as the disease progresses. Yet little attention has been paid to the experience and perspective of patients when they interact with physicians and the medical care system (Cotrell & Schulz, 1993; Downs, 1997). This neglect of the person with dementia has been expressed in the symptom diagnosis domain of medical encounters (see Figure 1). For example, symptomatic patients undergoing formal cognitive assessment have reported confusion and anxiety due simply to insufficient explanation about the purpose and meaning of such tests (Keady & Bender, 1998).

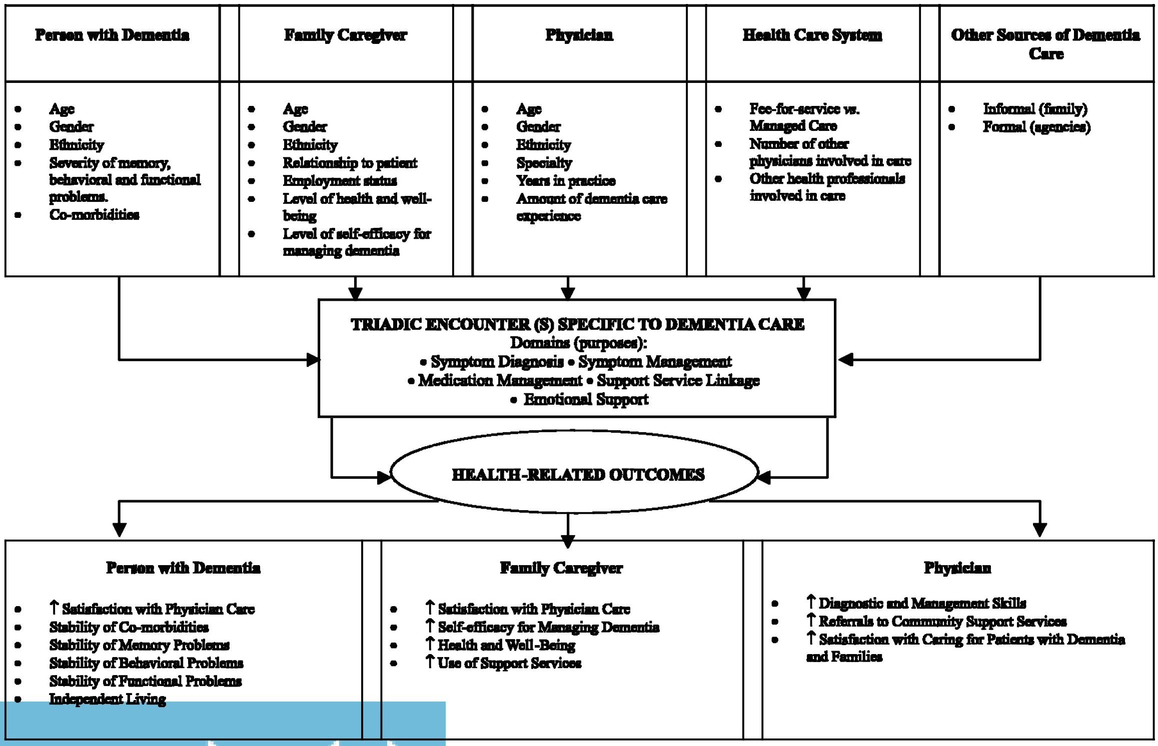

FIG. 1. Conceptual model of triadic dementia care encounters and health-related outcomes.

This could lead to a form of "white coat hypertension" in which the very presence of a diagnostic apparatus accentuates symptoms. As another example of patient neglect, physicians have reported a much greater likelihood of disclosing a diagnosis of probable Alzheimer's disease to a family member than to the person with the diagnosis (Fortinsky *et al.*, 1995). In future research, much more attention must be paid to the perspectives and involvement of the person with dementia during triadic medical encounters, and to variations in their involvement based on age, gender, ethnic background, and severity of symptoms (see Figure 1).

Second, as the dementia disease process progresses, the amount of emphasis placed on different domains of the triadic encounter is likely to change considerably. Smyth (1994) has noted that the emergence of staging models in dementia care enables members of the health care triad "to measure their experiences against typical cases and develop some sense of predictability and control" (p. 368) regarding dementia symptom diagnosis and treatment. Thus, staging of dementia is seen as a positive consequence of the medicalization of dementia (Miller *et al.*, 1992; Smyth, 1994). For example, in earlier stages of the dementia disease process, the major purpose of the triadic encounter is likely to be determination of a diagnosis. As dementia symptoms become more persistent and numerous, the purpose of triadic encounters will turn to symptom management (with or without medications) and use of home and community-based services. In the later stages of the disease, nursing facility admission and end-of-life care become paramount concerns for family caregivers. Aneshensel and colleagues (1995) have articulated the progression of the care-giving career against this backdrop of increasing illness severity and changing settings of service provision over time. Future research based on the model shown in Figure 1 should more carefully identify and measure relevant domains of triadic encounters based on the stage of dementia exhibited by patients, and on the stage of the care-giving career exhibited by family caregivers, whether a cross-sectional or longitudinal design is used. The selection of health-related outcomes also should take into account whether persons with dementia are in the early, middle, or late stages of the disease process (Fortinsky *et al.*, 1997).

Finally, recent studies have suggested that various medications may favorably affect the course of dementia, leading to temporary improvement in cognition and functional capacity for some patients (Larson, 2000). Implications of the emergence of "anti-dementia drugs" (Post & Whitehouse, 1998) for the triadic encounter are enormous, and virtually no research has investigated these implications. For example, as interest in these drugs increases among persons with dementia and their family caregivers, triadic encounters can become dominated by discussions of the merits and pitfalls of using these medications. More dramatically, anti-dementia drug therapy may enable the person with dementia to return to an active decision making role about his or her own care, causing family caregivers and physicians to negotiate issues for a second time (Post & Whitehouse, 1998). The linear progressive decline in cognition and function may no longer be linear for growing numbers of patients and family caregivers. The proposed framework can be used as a springboard for longitudinal studies on the impact of anti-dementia drugs on the quality of the triadic encounter and health-related outcomes.

The next section of this paper summarizes research traditions in social, behavioral, and clinical sciences that are integrated in the proposed framework. By borrowing concepts and methods from these research traditions, it may be possible to make new advances in our understanding of how to improve dementia care when family caregivers, persons with dementia, and physicians interact. Following this section, the limited knowledge base on this topic is summarized. The paper ends with a discussion of future research directions, and implications for clinical practice and public policy.

Related research traditions in social, behavioral, and clinical science

Older patient-doctor relationships

Over the past four decades, social and behavioral scientists and physicians have examined the physician-patient relationship and its consequences for both patients and physicians (Adelman *et al.*, 2000). Early work in the field of medical sociology was dominated by proponents of Parsons' sick role theory, which contended that patients were expected to comply with physician treatment, creating an asymmetrical physician–patient relationship (Parsons, 1975). Medical sociologist Elliot Freidson explained how the culture of medical education sustained professional dominance over patients, but also recognized trends emerging to challenge this dominance (Haug & Lavin, 1983). More recently, assumptions underlying this relationship have shifted from physician as professional purveyor of medical knowledge and patient as unquestioning recipient of medical knowledge, to patient as a more active participant in medical decision making (Haug & Lavin, 1983; Haug, 1994). Today, this "doctor/patient negotiating model" (Haug, 1996) is increasingly commonplace due to economic influences of managed health care, direct marketing of pharmaceutical products to consumers, and rapid growth of medical information via the Internet. It is also increasingly recognized that medicine is not an exact science, and that a considerable amount of uncertainty exists in the diagnosis and treatment of many health problems (Gerrity *et al.*, 1992).

These themes of increased consumerism and uncertainty in medical care are accentuated in the older population, conventionally defined as age 65 or older. In terms of sheer volume of interaction, older adults visit the doctor more frequently than do younger persons and the frequency of older patient–physician encounters is expected to continue increasing for the foreseeable future due to the aging of our population (Beisecker, 1996). Because the older population now spans 2–3 generations, however, it is difficult to generalize about older patients in the context of medical encounters (Adelman *et al.*, 2000). For example, the "young–old" are more likely than the "old–old" to engage in a negotiating model of interaction with their physicians, while the "old–old" are more likely to have multiple health problems that lead to greater physician uncertainty (Beisecker, 1996). Nevertheless, in the few studies on older patient–physician communication patterns that have been carefully conducted, physicians have been found to engage in "ageist" behavior when meeting with older patients. Ageism leads physicians to trivialize medical problems and attribute them to the natural aging process. This attitude may lead older patients to be more passive and allow physicians to make decisions for them. However, neither the magnitude of ageism in older patient–physician interaction nor its consequences have been systematically studied (Adelman *et al.*, 2000). Indeed, despite the availability of theoretical traditions in medical sociology and behavioral psychology (e.g., stress-coping theory and social learning theory, both discussed below), most physician–older patient communication research has proceeded without theoretical guidance. Simply put, "no theory to explain behavior during geriatric medical encounters has become widely accepted." (Beisecker, 1996, p.24).

Addition of the "third person" in older patient–physician encounters

Recognition of the family caregiver as the "hidden patient" in medical encounters first arose during the 1970s in family medicine and gerontology (Medalie, 1994). The concept of "health care triad" has emerged in gerontology and geriatrics to describe encounters and interactions among older patients, family caregivers, and physicians (Adelman *et al.*, 1987; Adelman *et al.*, 2000; Haug, 1994). From a clinical perspective, Silliman (1989; 2000) has concisely, and persuasively described the importance of the family member as a third person in the geriatric medical encounter. Families provide a multitude of tasks for frail older relatives and often accompany them to physician visits; hence, their involvement in medical encounters is critical. This triadic clinical relationship is dynamic, and "the nature of the relationship varies over time in accordance with both patient and family needs, and the course of patients' medical conditions and functional status." (Silliman, 2000, p.55).

Empirical studies of family member participation in geriatric medical encounters have been quite limited, and based on small samples, but several findings are noteworthy. First, depending on the study, up to nearly 60 percent of older patients are accompanied by a third person to a medical visit, and the same person tends to accompany older patients over multiple visits (Adelman *et al.*, 2000; Prohaska & Glasser, 1996). Second, the addition of a family member leads the physician to rely on the family member for information that otherwise could be obtained from the older patient, relegating the patient to the role of passive participant (Greene *et al.*, 1994). Third, behaviors that support older persons to engage in self-care activities are less apparent when a third person joins the encounter (Hasselkus, 1994). Fourth, uncertainties are compounded in triadic encounters because of the multiple roles and agendas that third parties may bring to medical encounters (Hasselkus, 1994; Prohaska & Glasser, 1996). Fifth, the more impaired the older patient, the more protective the third party is of the patient (Hasselkus, 1994). Sixth, physician–patient–family caregiver interaction during office visits change over time to the point where all communication occurs between physicians and family caregivers (Beisecker *et al.*, 1997). Finally, older patients regard the third person as an asset during medical encounters, as well as before and after physician visits; in terms of helping them make important medical decisions (Prohaska & Glasser, 1996). It is important that only one of these studies (Beisecker *et al.*, 1997) involved information about patients with a principal diagnosis of Alzheimer's disease or other dementia. To date, no known studies have been published in which triadic encounters have been examined where all older patients have dementia. Nevertheless, family caregivers, as the most frequent third party in medical encounters, clearly alter interactions that would otherwise occur in a more traditional older patient–physician encounter.

Stress-coping-social support-health paradigm

The dominant paradigm used by social and behavioral scientists in family caregiver research is based on the stress and coping model (Lazarus, 1966), developed most creatively in the work of Pearlin and colleagues (Pearlin & Schooler, 1978; Pearlin *et al.*, 1990). In elaborating on the stress process underlying family care for relatives with dementia, Pearlin and colleagues (1990) presented a conceptual model linking the background and context of stress, the immediate sources of stress, mediators of stress (coping and social support), and the outcomes or manifestations of stress. Proponents of the stress and coping model have examined relationships between personality characteristics of caregivers and their coping styles (Fleishman, 1984; Hooker *et al.*, 1994).

They also have articulated the impact of caregiver burden and coping styles on physical and mental health and well-being measures (Pruchno & Resch, 1989; Schulz *et al.*, 1990). In the context of dementia care, another valuable contribution of this paradigm has been the development of a wide array of family caregiver outcomes based on self-reported symptoms as well as physiological measures of health and well-being (Kiecolt-Glaser *et al.*, 1991; Ory *et al.*, 1999; Schulz *et al.*, 1995).

This line of research has helped underscore the practical value to family caregivers of developing coping skills to address the stresses associated with having cognitively and behaviorally impaired older relatives. The importance of social support as a mediator of stress also helps explain why family caregivers turn to physicians for support during and between office visits (Silliman, 1989). However, very little research in the care-giving stress tradition has focused on the role of the physician as a source of social support. Instead, nearly all studies have examined either other informal caregivers, or support provided directly by service agencies, as means of alleviating the manifestations of care-giving stress (Haug, 1994).

The stress-coping social-support health paradigm offers a critical, but incomplete, set of constructs for capturing key aspects of family caregiver–physician–person with dementia encounters and interactions. During interactions with physicians, family caregivers need practical medical advice and informed guidance that will help them make informed choices about how to manage their relatives most successfully. Equipped with adequate knowledge, caregivers would become "psychological activists" (Thoits, 1994), proactively shaping their lives as caregivers. The paradigm of social learning and self-efficacy accounts for this important element in dementia care triadic interactions.

Social learning-self-efficacy paradigm

Perceived self-efficacy is the belief that one can perform a specific behavior or task (Bandura, 1991; Lorig *et al.*, 1989). The distinguishing feature of self-efficacy is its reliance on behavior-specific domains to describe how certain or confident individuals believe they are in taking specific actions. For example, self-efficacy measures have been developed for health related behaviors and problems such as smoking and pain control (Bandura *et al.*, 1987; Coletti *et al.*, 1985; Ryckman *et al.*, 1982). In the context of chronic illness, perceived self-efficacy presumes that individuals have the capacity to assume control over their situations by learning about key aspects of care (Bandura, 1991; Holman & Lorig, 1992; Lorig *et al.*, 1989). For example, measures of self-efficacy for pain management, exercise, and medication management have been devised for persons with arthritis (Holman & Lorig, 1992; Lorig *et al.*, 1989; Lorig *et al.*, 1993) or osteoporosis (Horan *et al.*, 1998).

Much less work has been done to adapt the concept and measurement of self-efficacy to family caregivers of persons with chronic illness. Family caregiver self-efficacy is especially important to consider when older relatives have Alzheimer's disease or another dementia, because as this disease process progresses, the care-giving career increasingly includes responsibility for carrying out specific care and care management behaviors (Aneshensel *et al.*, 1995; Fortinsky & Hathaway, 1990). Measures of family caregiver mastery and competence have been developed (Lawton *et al.*, 1989; Pearlin *et al.*, 1990), but these represent global constructs without reference to specific behaviors or tasks.

Recently, several investigators have begun developing measures of family caregiver self-efficacy that are more domain-specific. For example, a measurement approach for "coping efficacy" among caregivers of persons with dementia focused on how often caregivers reported ways of dealing with stressors (Gignac & Gottlieb, 1996). Haley and colleagues (1996) briefly described a measure of family caregiver self-efficacy (i.e., confidence) in managing dementia-related problems. Zeiss and colleagues (1999) reported on the development and testing of caregiver self-efficacy scales covering two domains: caregiver self-care and problem solving to cope with the daily challenges of care-giving. A revised version of these scales was also recently tested for reliability and validity, covering three domains: obtaining respite, responding to disruptive patient behaviors, and controlling upsetting thoughts (Steffen *et al.*, in press). Finally, caregiver self-efficacy measures incorporating the domains of dementia symptom management and community support service use have also recently been developed and tested (Fortinsky *et al.*, under review). Future research should employ such measures of caregiver self-efficacy as outcomes to help judge the effectiveness of triadic dementia care encounters with primary care physicians or other health care professionals.

Quality of medical care research

Over the past decade, considerable advances have been made in our understanding of how to conceptualize and measure the quality of medical care and its consequences for consumers in the United States. Indeed, one of the most widely adapted conceptual models of health care use in social and behavioral science by Andersen and colleagues (see Andersen, 1995 for a review) was developed with a goal of improving the quality of health care. The Medical Outcomes Study (Tarlov *et al.*, 1989) has attracted social, behavioral, and clinical science investigators to questions about how and why health-related outcomes in users of the medical care system are associated with important clinical and administrative characteristics of health care providers and health systems. Andersen's recent revision of his conceptual model highlights the importance of considering health-related outcomes as potential consequences of differential use of health services (Andersen, 1995).

The vocabulary and methodology of quality of care research has penetrated health care practice and policy over the past decade. Among managed care organizations in the private health care sector (primarily for younger consumers), reports of satisfaction with medical care are used increasingly as health-related outcome measures to determine the quality of ambulatory medical care. In the public sector, the U.S. Health Care Financing Administration (HCFA) has for nearly a decade, supported the development of standardized quality assurance programs for Medicare and Medicaid beneficiaries (primarily older consumers) receiving home health care and nursing facility care throughout the United States. However, consumer reports of quality in these settings are not presently incorporated into these quality assurance systems as outcome measures. Moreover, uniform quality assurance systems of any type are nearly non-existent in ambulatory care settings where Medicare beneficiaries (more than 85 percent who remain in the fee-for-service Medicare program, not managed care plans) visit physicians for primary medical care.

Stewart and colleagues (2000) reviewed a considerable amount of literature on the influence of older patient and physician communication on health-related outcomes. They noted that most studies and their conclusions are based on small samples, and that few statistical associations between measures of communication and health-related outcomes have been studied in depth. Patient satisfaction and adherence with medications have been studied most frequently. While these authors noted the greater inclusion of a third person into the medical encounter, they concluded: "conflicting data remain on the impact of this person on the patient–physician relationship and health outcomes." (p. 28).

Knowledge base: research on family caregiver-physician interaction in dementia care

Survey research with family caregivers

Numerous studies based on family caregiver interviews have found that family caregivers report some degree of dissatisfaction with physician care during the dementia diagnostic process and after a diagnosis of dementia is reached (e.g., Beisecker *et al.*, 1997; Chenoweth & Spencer, 1986; Fortinsky & Hathaway, 1990; Glosser *et al.*, 1985; Haley, *et al.*, 1992; Morgan & Zhao, 1993). Studies to date, however, have used diverse approaches to measuring aspects of the medical encounter with which family caregivers are dissatisfied. Moreover, no known published studies have examined how caregiver views of the dementia care medical encounter are associated with caregiver or patient outcomes. Therefore, research in the area of physician-family caregiver relationships and interaction is still in early stages of development (Haug, 1994; Morgan & Zhao, 1993).

Uniform concepts and measurement approaches must be developed by researchers to help articulate domains and quality of family caregiver–physician (and, by extension, triadic) interactions specific to dementia care. Haley and colleagues (1992) pioneered research in this area by using family caregiver ratings on 23 statements to assess their satisfaction with physician care. Three domains of physician care were determined and identified by factor analysis—level of information received from physician; physician sensitivity to affective aspects of care; and level of physician control. This study found that caregivers were most dissatisfied with the level of information domain, and most satisfied with the level of physician control. Other family caregiver studies have found that their most important concerns when interacting with physicians about dementia care are: (1) obtaining a diagnosis; (2) learning how to manage current or expected symptoms; (3) locating and using support services in the community; and (4) receiving emotional support (Beisecker *et al.*, 1997; Connell & Gallant, 1996; Fortinsky & Hathaway, 1990; Glasser & Miller, 1998; Malone-Beach *et al.*, 1992). Family caregivers are also increasingly requesting information about medications to relieve dementia-related symptoms, and this domain of interaction will continue to grow thanks to advances in pharmaceutical science (Post & Whitehouse, 1998; Larson, 2000). These five domains of concern to family caregivers are set forth in Figure 1 as the major domains, or purposes, of triadic dementia care encounters.

In an effort to measure the quality of interaction during dementia care encounters based on the proposed conceptual model, Fortinsky and colleagues (2000a) asked family caregivers a series of 12 questions about their experiences with physicians in four of the five domains illustrated in Figure 1—symptom management; medication management; support service linkage; and emotional support. Three questions were asked within each domain. Caregivers responded "yes" or "no" to each question based on whether the physician had provided advice or guidance about the specific topic mentioned in the question (e.g., Did the doctor give you information about agencies that offer services to help you care for your relative? Did the doctor give you information about possible side effects from prescribed medication your relative is taking?). Among the more than 150 caregivers who answered all 12 questions, the mean number of "yes" responses was 5.1 (range = 0–11). Medication management was rated the best (mean =

2.2 "yes" responses out of a possible 3), while support service linkage was rated the worst (mean = 0.3 "yes" responses out of a possible 3). Preliminary findings indicated that these quality measures were not associated with caregivers' gender, relationship to person with dementia, nor ethnicity (Fortinsky, 2000a). Much more research is needed to refine and replicate interview-based measures of the quality of dementia care interaction between family caregivers and physicians across all five domains of interaction as illustrated in Figure 1.

Survey research with physicians

Several studies of physicians based on survey research techniques have found considerable variation in reported dementia diagnosis approaches, with physicians often conducting inadequate diagnostic tests compared to clinical practice guidelines (Downs, 1996; Fortinsky & Wasson, 1997; Glasser, 1993; Rubin *et al.*, 1987; Somerfield *et al.*, 1991). These practice variations stem in part from the variable knowledge base that physicians report with regard to risk factors for Alzheimer's disease and appropriate diagnostic workups, as found by Brown and colleagues (1998) in a national survey using the University of Alabama at Birmingham Alzheimer's Disease Knowledge test. In a recently published study, Boise and colleagues conducted focus groups with physicians to learn about barriers to adequate dementia diagnosis (Boise *et al.*, 1999). Reported barriers included physician failure to recognize and respond to symptoms, limited time, perceived lack of need to determine a specific diagnosis, and negative attitudes toward the importance of dementia diagnosis and management. Three significant findings from this study were: (1) physicians were reluctant to determine a specific diagnosis because of the stigma attached to the term Alzheimer's disease; (2) physicians believed it was futile to determine a diagnosis unless and until effective drug therapies were available for their patients; and (3) family caregivers exercised considerable control over the degree of diagnostic aggressiveness pursued by the physicians.

Less is known about the quality or content of the medical encounter after a diagnosis of dementia has been made, from the physician's viewpoint. In a clinical vignette-based study portraying an older female patient diagnosed with probable Alzheimer's disease and her adult daughter, primary care physicians with the following characteristics were found to be more likely to discuss symptom management issues and refer to community support services—family physicians; more recently trained physicians, and physicians with more dementia care experience (Fortinsky *et al.*, 1995). These background characteristics are taken into account in Figure 1 in this paper, and should be incorporated into future triadic encounter research in dementia care. Another study found that physicians with more dementia care experience (i.e., more patients with dementia in their practices) were more likely to refer their patients and their families to the local chapter of the Alzheimer's Association, respite care, and adult day care services in the previous year. Physicians in this study also overwhelmingly preferred sharing ongoing dementia care responsibilities with such specialized dementia care services (Fortinsky, 1998). These results from the physician perspective strongly suggest that triadic dementia care encounters should not be studied without accounting for the larger information and support service system that may influence the medical encounter as well as patient and caregiver outcomes. These other sources of information and support are also incorporated into Figure 1.

Parallel survey research with caregivers and physicians

In a widely cited study based on 57 physician and caregiver pairs, Glosser and colleagues (1985) found that physicians and family caregivers agreed that physicians were most helpful in explaining the diagnosis and prognosis of dementia. Physicians also reported that linking families with support services in the community was their most difficult task, and family caregivers believed this was the physicians least helpful activity. In a recently published study of 15 physician and caregiver pairs, Glasser and Miller (1998) developed standardized statements to evaluate medical encounters regarding dementia care. They found that caregivers reported physicians as more limited in assisting them with non-medical management and psychosocial issues. Moreover, physicians rated themselves more highly on these dimensions of practice than did caregivers. This study suggests that physicians are concentrating on diagnosis and medical management during office visits, and are continuing to fall short of caregivers' expectations in terms of symptom management advice, support service advice, and interpersonal skills with caregivers during medical encounters.

Survey research with persons with dementia

No known published studies have interviewed persons with dementia about their encounters with physicians, or about their encounters with family members regarding their dementia care. Although the knowledge base is presently rudimentary, several efforts are presently underway to improve quality of care and health outcomes measurement in older adults with cognitive impairment and/or diagnosed dementia. For example, the Picker Institute in Massachusetts has been awarded funds from an anonymous donor "to systematically investigate the quality of care and well-being for individuals with early stage dementia" (Unpublished written communication from A. Stern and E. Sullivan, January 7, 2000). Researchers in this study are convening focus groups of persons with dementia, family caregivers, and staff at supervised living facilities where persons with dementia reside, to develop tools to measure and improve the quality of dementia care. In an ongoing research and demonstration study, the Cleveland Alzheimer's Managed Care Demonstration, more than 100 persons with dementia have been interviewed about the medical care they receive from physicians and other staff in their managed care organization. This study is a collaboration between the Cleveland Area Alzheimer's Association, Kaiser Permanente of Ohio, the Benjamin Rose Institute in Cleveland, the University Alzheimer's Center at University Hospitals of Cleveland and Case Western Reserve University, and the University of Connecticut Center on Aging. At the time of writing, preliminary results from the baseline interview are unavailable.

Future research directions and unanswered questions

Summary of knowledge base

To summarize major points about empirical research, our current state of knowledge about interaction between persons with dementia, family caregivers, and physicians is based largely on survey research with family caregivers, supplemented by a smaller body of survey research with primary care physicians. To date, virtually no dementia care research has included parallel surveys of physicians and family caregivers, and no known published research has examined the medical encounter from the perspective of the person with dementia (although efforts are currently underway to gain this perspective through survey research). Observational research on geriatric medical encounters has been largely restricted to older patient and physician interactions in the absence of dementia as a major health problem in study samples. Based on this limited body of research, the irrefutable conclusion is that interactions in medical encounters when dementia care is discussed are far from optimal from the perspectives of both family caregivers and physicians. Another key conclusion is that many physicians are willing to share ongoing management of dementia patients and their families with other organizations in the community. Finally, based on indirect evidence and clues from related research, older persons with dementia, even though physically present during triadic encounters, are unlikely to be involved as active participants in dialogues and decision making regarding diagnosis and management of dementia symptoms.

Future research directions and unanswered questions are presented at the levels of theoretical schools of thought, the integrative conceptual framework presented in this paper, design and measurement issues, and health care practice and policy arenas.

Theoretical integration

Nearly all research in the field of health care triads and dementia care research has been atheoretical, yet, there is no shortage of informative social and behavioral science theories which could influence future directions in this field. As noted earlier, both the stress-coping social-support school and the social learning self-efficacy school offer important insights into the domains of communication that could be examined between persons with dementia, family caregivers, and physicians. For example, if we assume that the patient and the family caregiver wish to be educated and wish to gain some level of emotional support from medical encounters with physicians, then investigations could be organized around specific domains of education and support. Principles of medical uncertainty and professional dominance *vs.* negotiated care, borrowed from the broader field of physician–patient communication, could serve as an additional theoretical lens through which to observe and measure interaction in the triadic dementia care encounter. Family systems theory, not previously discussed in this paper, could also be adopted as a theoretical framework to examine how persons with dementia and family caregivers from family systems of different levels of functionality or dysfunction interact with physicians about dementia care issues (Lieberman & Fisher, 1999). Finally, any investigation of triadic encounters that intends to have relevance to health care practice and policy should consider borrowing from the quality of medical care theoretical framework and link domains of the process of care (i.e., the interactions themselves) with appropriate health-related outcomes of care.

There are considerable numbers of investigators from the social, behavioral and clinical sciences interested in how family caregivers, persons with dementia, and physicians interact during the course of the dementia disease process. Investigative teams that combine social and behavioral scientists with committed clinicians and clinician–scientists are optimal for testing hypotheses that could be generated from these diverse yet complementary theoretical traditions. Cross–national investigative teams and studies on health care triads should be initiated over the next decade, as dementia care issues affecting patients, families, and physicians are very similar in most developed countries (Fortinsky, 2000b).

Proposed conceptual model as a springboard

The conceptual model presented and discussed in this paper is intended to help integrate various theoretical and methodological traditions so that the elements in the model can be sharpened into useful variables and interrelated in order to test important hypotheses that would help improve dementia care. Characteristics of persons with dementia, family caregivers, and physicians included in this model have either been found or hypothesized to influence medical care of older patients, or have been linked to patient or family caregiver outcomes in this model. Characteristics of the health care system, and other sources of dementia care information, could be included in future research as either principal variables of interest, or as covariates, when factors influencing dementia care interactions in medical encounters are studied. Examples of research questions that could be answered based on this framework (and that have not been answered to date) are:

- How do socio-demographic characteristics of family caregivers, persons with dementia, and/or physicians influence the quality of triadic interactions regarding dementia symptom diagnosis and management?
- How do characteristics of the health care system (e.g., fee-for-service *vs.* managed care, Medicare coverage for persons with dementia) influence the quality of triadic interactions regarding dementia symptom diagnosis and management?
- To what extent does the quality of triadic interactions regarding support service linkage result in improved family caregiver self-efficacy for accessing support services, as well as actual use of such services (e.g., respite care, adult day care, support groups)?
- How does the quality of triadic interactions regarding medication use and management influence stability of the patient's medical and behavioral problems, and improved mental health in family caregivers?
- How important is the quality of dementia care interactions with physicians, compared to information received by persons with dementia and family caregivers from other informal and formal sources, in improving health-related outcomes?

Variable measurement and study design

Social and behavioral scientists have barely begun to develop and test measures of communication domains common to the dementia care encounter. Using Figure 1 as an example, fundamental work is needed in the area of medication management, and consensus among active researchers is needed to construct multiple-item measures of the more-often studied domains of symptom management, support service linkage, and emotional support. If survey research is the chosen data collection approach, rating scales must be developed for patients, family caregivers, and physicians. If observational research is the chosen approach, methods of determining how to document and measure communication in each domain must be devised.

Family caregiver outcomes measurement is most highly developed in the area of health and well-being, where measures of burden, physical health, and mental health have been used for some time. This state of the field reflects the predominance of the stress-coping model in care-giving research to date. Measures of outcomes based on social learning and self-efficacy theory, however, have not been widely used. Ideally, future research should devise and test family caregiver (and perhaps patient) self-efficacy measures that parallel the domains of communication between family caregivers and physicians (e.g., symptom management, medication management).

Longitudinal studies of dementia care triadic interactions and their outcomes are sorely needed. Existing longitudinal studies of care-giving have not systematically examined the role of primary care physicians in the lives of family caregivers. Well-designed longitudinal studies would help clarify how the domains of dementia care triadic encounters change in importance as the dementia disease progresses.

Health care practice and policy research areas

Unanswered questions and issues also loom in the more pragmatic arenas of health care practice and public policy. For example, to what extent should research and demonstration projects be encouraged to improve physician communication and dementia care practices with patients and family caregivers? A randomized trial is currently underway in Great Britain to test the effects of enhanced dementia education for general practitioners using interactive computer modules (Downs & Iliffe, 1999). Physician practice guidelines for dementia diagnosis and treatment have recently been published by a number of organizations (e.g., American Medical Association, 1999; Costa *et al.*, 1996; Small *et al.*, 1997). The national Alzheimer's Association plans to develop and test the feasibility of care coordination models, possibly involving primary care physicians, to improve caregiver outcomes (Alzheimer's Association, 1999). Should such interventions be tested in the United States, in either managed care organizations or primary care physician networks? At the level of public policy reform, should Medicare, Medicaid, and other health insurance/entitlement (Older Americans Act) benefits be modified or pooled to enhance dementia care by physicians and other sources of education and direct services for persons with dementia and their family caregivers and if so, how? The proposed framework in this paper could be used to conceptualize variables that should be taken into account to assure thoughtful evaluations of efficacy or effectiveness if, and when, such intervention trials are planned and implemented.

What role will technology and telecommunications advances play in influencing dementia care interactions between physicians, family caregivers, and persons with dementia? How could such changes be captured and measured in well-designed studies? Haug (1994, 1996) was among the first to note the potential effects of technology on health care triad interactions and expanded communication. For example, Adelman and colleagues (2000) discussed the explosive growth in e-mail medical information and its implications for privacy, and consent to share medical information. How could e-communication enhance the quality of triadic encounters specific to dementia care, and could this technology favorably affect outcomes? Telemedicine is increasingly used for improving health care to geographically distant consumers, and may be able to assist physicians in rural areas who require greater resources to adequately diagnose and manage their patients and families affected by dementia. Even where resources are available to physicians, preparing for physician visits is often very stressful for persons with dementia and their caregivers; therefore, telemedicine may help reduce number of necessary office visits, improve behavior problems in patients, and improve health and well-being of caregivers. Internet communication technology is also providing a vast reservoir of online information about dementia care to family caregivers and patients. As George Lundberg, editor-in-chief at Medscape, an online health information service, recently noted: "It's no longer 'the doctor knows best'. We are going to see more patients…empowered by the electronic age, and physicians will have to adapt to this"(Julien, 2000). These sources of dementia care information could be incorporated into the proposed conceptual framework as "other sources of dementia care information", and may be viewed as either informal or formal sources of information.

Finally, several trends that promise to affect triadic interactions in the future include: increasing interest in detecting mild cognitive impairment; increasing focus on sub-clinical impairments that may suggest a greater risk for developing dementia; and rapid advances in genetic testing for dementia in the absence of symptoms (Haley and Mangum, 1999). These trends reflect the potential creation of an additional domain of triadic interaction that precedes symptom diagnosis.

Concluding note

This paper has focused on family caregiver and patient interaction with physicians in the office setting. Broader views of the medical care system were briefly discussed but not featured. Nevertheless, research is sorely needed in other health care settings where patients and family caregivers interact with physicians and other health professionals to better understand how dementia care communication and practice are carried out, and with what consequences. This is especially true when patients with dementia are entering or leaving a new health care setting. For example, emergency department care, the hospital discharge planning process, assisted living facility admission process, skilled nursing facility discharge process, and the home health care admission and discharge process, are all critical points of interaction where patients and family caregivers affected by dementia could stand to lose or gain from high quality communication. Both the role of the physician in these encounters, and the quality of interactions among health professionals, family caregivers, and patients, are poorly understood. Answers from well-designed investigations in these settings could improve research knowledge, practice, and public policies for the growing numbers of older adults and family caregivers facing long years of care due to Alzheimer's disease and other types of dementia.

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