

The Congregation-Healing Institution Connection

In January 1988, the University of Texas M. D. Anderson Hospital hosted the First National Conference on Outpatient Ministry. The objective was to explore the relationship between the healing institution and the community, with respect to the spiritual needs of patient populations in general, and outpatients in particular. Strange to confess, we noted that when we began to explore the nature and scope of outpatient services, we started with the assumption that our investigation was restricted to the boundaries of our assigned clinics. During planning for the conference, however, as the boundaries were dissolved, we began to see patients in *their* locations, which were not hospitals but their communities.

A patient's visit to an outpatient clinic absorbs a few hours (although all too often that became an entire day), but home and other responsibilities and relationships await them. Some health care professionals too glibly refer to holistic medicine but confine that term to the involvement of a multidisciplinary team in the hospital segment of the patient's life. Both Lawrence E. Holst and Herbert Anderson remind us that, among their other roles, institutional chaplains are called to exercise an advocacy as well as a prophetic function within their institutions and within their faith groups.¹ This must apply within the outpatient clinic programs in our hospitals where medical care normally depends on the multidisciplinary team, to which the patient's pastor or rabbi might, in some cases, make a significant contribution but is almost universally overlooked. Institutional chaplains have not challenged medical or nursing staffs with sufficient vigor to view patients as members of families and communities, and often of congregations. Nor have chaplains taken with sufficient seriousness the opportunities that exist to establish links between the limited spiritual ministry the institution can offer and the broader care that encompasses the patient's life beyond the hospital. The question is what steps we may take to facilitate conversations between the healing institution and the congregation.

The Congregation as the Locus of Spiritual Care

One of the tasks of institutional chaplains—and one of the important reasons for outpatient spiritual care—is to ensure that patients are perceived as people whose location is not the hospital but the community. Chaplains should support patients' primary spiritual caregivers, lay and ordained, and their congregations as a primary objective of patient care. Since congregational clergy/rabbis fulfill a

¹ Herbert Anderson, Lawrence E. Holst, & Ronald H. Sunderland (Eds.) *Ministry to Outpatients* (Minneapolis: Augsburg press, 1991), p. 80.

much more intensive function than chaplains can in their brief patient encounters, the healing institution should view patients' pastors and rabbis as partners, instead of regarding clergy and rabbis as mere adjuncts chaplains' services. Chaplains thus find their fulfillment in the servant role demanded by scripture.

Strengthening the Connection between the Healing Institution and the Congregation

The development of firmer bonds that link the healing institution, the congregation, and its member families is a task that awaits us. It is assuming greater urgency as stresses in the health care delivery system threaten the nation's care of its citizens. Shortened hospital stays, recourse to day surgery, and greater emphasis on outpatient services, while producing some benefits, place heavier burdens on families which must provide services previously available in institutions. Inflation of hospital, medical, pharmaceutical, and insurance costs erodes the financial resources of many families and exacerbates stresses. As the U. S. population ages, and the number people 85 years and older increases, the situations of many families will be further complicated by the responsibility of caring for frail seniors.

Until the mid-80s community-based programs customarily provided one-on-one volunteer-client services that included friendly visits, shopping assistance, some transportation, delivery of meals-on-wheels, reassurance phone calls, and the like that a single volunteer could provide weekly or less frequently without undue burdens being placed on single volunteers. Such services continue to meet the needs of most seniors, for, as J. W. Rowe and R. L. Kahn noted² most adults age 'successfully'. Rowe and Kahn make the case that the positive aspects of aging have been terribly overlooked—aging people are taking better care of themselves and science and medicine are taking better care of people.

Nevertheless, many members of the old and 'oldest-old' cohorts do not age successfully, at least in terms of their failing health status. The frequency of functional impairment and chronic disease increases with age. Nearly 50 percent of people aged 85 years and over have impaired hearing; vision impairments, falls, hip fractures, stroke, cancer, and cardiovascular disease become more common. Moreover, nearly half have some type of dementia. As outpatient care fills a larger role in patient care, the potential—and the importance—of the links between healing institution, patient, and congregation grows.

² John W. Rowe and Robert. L. Kahn, *Successful Aging*, [New York: Pantheon Books, 1998]

As a consequence, the Houston Care Team model becomes even more crucial as a means of developing and sustaining that network.

Most member care is provided to congregants by individual church or synagogue staff or laypeople. Counseling of members, hospital and bereavement visits, and other routine home visits are usually one-to-one relationships, and are effective in meeting most members' needs. These more typical services, however, do not address the needs of families caring for loved ones who are chronically ill or catastrophically disabled and who require constant, intensive attention. Unremitting demands on caregivers' physical and emotional support often saps caregivers' health, leaving them less and less capable of sustaining their loved ones in the home. Until the development of the Care Team model, there was lacking a formal, structured means to bring these families into the regular life and awareness of the congregation. Families with overwhelming special needs often just drop through the cracks and out of sight.

The Care Team program works by assigning members to each family in groups—*Care Teams*—such that support tasks are shared among the members, and no one individual is left with the sole responsibility of meeting the individual's or family's needs. The following family situations are typical of the claims on congregations' compassion and care:

Jeannette is a single mother of two school-age children. Following an auto accident that left her a quadriplegic, wheelchair-bound adult of 43 years, her husband deserted her. Jeannette initiating divorce proceedings, and her mother, who works during the day, moved into the home. Jeannette is incontinent of bowel and bladder, and requires a diaper change by mid-day. She now has a Care Team consisting of 6-8 women who are scheduled to attend to her needs on a daily basis. Of course, team members not only assist with physical tasks, but as they do so, reassure Jeannette and her family that their congregation stands with them.*

Mary is aged 68 years, and is legally blind but otherwise in sound health. Unable to read, and living alone, her problems multiplied. She could not read her utility bills in order to write her checks. Unable to drive, she could not attend worship and with no sidewalk between her residence and the nearby stores, was unable to shop. Mary's Care Team is an inter-generational group of eleven people, including a young married couple and their two pre-school children, three high school seniors who assist her with reading and writing chores, and four adults who provide her with peer companionship and transportation.

Robert was diagnosed with carcinoma at the age of 57. The cost of his medical care has absorbed the family savings, and his wife, Betty, is the family's only source of income. The recommended course of radiotherapy and chemotherapy requires him to attend the hospital's outpatient clinics for an extended period. Since Betty cannot take any more time off from her work, Robert has a team of six members who carry him to and from the clinic, in the course of which they meet his needs for companionship and emotional support.

*Elizabeth's husband, Tim, has Alzheimers disease. Their three married children all live out-of-state. His increasing dependence on her demanded more and more of Elizabeth's attention and she was finally forced to resign from her employment her absence was not noticed by. Three years later, she had not attended worship during the three years, and fellow members and the congregation's staff had not noticed her absence! Elizabeth's Care Team members attend an early worship service, then relieve her of Tim's care so that she can attend the 11.00 a.m. service. She wrote: "Tim has asked me when Tom and Earl will come again. Together, we thanked God for you, and prayed you would come again soon. Thank you from the bottom of my heart. May God bless you!" (*Names have been changed to protect privacy).*

It is to assist congregations to respond to situations of these intensities and urgencies that the Care Team response is proposed. *Interfaith CarePartners, Inc.* pioneered the Care Team model under its former title, the Foundation for Interfaith Research and Ministry (FIRM). FIRM was incorporated in Houston in 1988, and the name change was effected in 2000. The organization's principals, Earl E. Shelp, Ph. D. and Ronald H. Sunderland, Ed. D., designed the Care Team model in 1985 in response to the growing HIV/AIDS epidemic and extended its application in 1992 to families caring for loved ones with demential diseases. The model was expanded still further in 1994 to care for frail seniors with other than dementia-related in-home needs.

The inception of the Care Team concept was a response to individuals and their caregivers stricken with chronic and terminal health conditions, including severe physical impairments, whose needs are so intense and so extensive as to overwhelm customary, one-on-one volunteer-client relationships. They constitute the cohort making the greatest demands on communities and are most likely to be overlooked because their needs are so overwhelming that they require not a monthly or even a weekly friendly visit but in-home care two or three days each week. Apart from those families financially able to purchase in-home support, individuals and their caregivers lacking those resources often slip through the

cracks, or, to change the metaphor, fall through tears in the social fabric. The overwhelming nature of their physical needs is beyond the ability of the traditional one-on-one volunteer-based programs, wears out volunteers rapidly, and may strain communities' limited fiscal resources.

This cohort consists not only of low-income individuals and families, but includes many middle class families. Families whose income level or assets excludes them from Medicaid and other government-subsidized support often find their financial resources are inadequate to provide a protracted period of care for chronically ill or severely impaired members. Their resources are drained by the high cost of health care, medications, and other expenses ancillary to their health status. A typical example is the family that loses hospice care when services are terminated because the patient outlives the mandated six-month period of Medicare support. But families are trapped in many other situations. Caregivers of dementia patients who desire to care for frail loved ones in-home, or are forced to do so because they cannot afford institutional care, may forgo employment in order to provide the level of supervision necessitated by loved ones' increasing needs. Further, many long-distance caregivers of frail seniors are confronted with the dual challenges of being unable to provide personal care and the costs of obtaining paid services or of frequent out-of-state visits.

The Care Team model is uniquely structured to respond to the often-overwhelming needs of such families. Team members visit in pairs, and four to eight members may be assigned to each family, depending on the extent of need. This format enables teams to provide in-home support 2-3 days per week, and more frequently when indicated, without individual team members being over-burdened by their tasks. Monthly Care Team meetings facilitate oversight of members' services, regular in-service training, presentation of in-take information concerning new clients to the entire team, assignments of members, and other functions that contribute to the efficient management of team services. Based on our fifteen-year experience, we believe the optimal volunteer program incorporates initial orientation to the project infrastructure and types of services it will provide client families. Thereafter, volunteers benefit for clinical oversight of those services. That is the Care Team model is based on the assumption that learning is reinforced when the experience of caring raises issues that are then presented for supervision.

Local congregations have a number of assets that emphasize their potential as sources of volunteers and as a stable foundation on which to build the program. First, religious congregations by the nature of their identity and commitment are called to serve their communities. They are committed to

care, and they have a history of doing so. While not every individual member is called to undertake such services, representative lay members *are* identified and called to serve on the congregation's behalf.

Second, the nature of congregational membership facilitates the bonding of members into a cohesive group motivated by their common identity as congregants. This is not to argue that secular-based groups of volunteers do not bond and form cohesive cadres. Rather, congregants are accustomed to doing so—it is part of the nature of congregations to use group processes to structure and support their programs.

Third, the keystone to efficient management of volunteers is local, on-site, structured oversight, or supervision that includes at least one monthly meeting for reports and review of volunteers' functions. Monthly meetings include both basic training in listening skills and continuing education that supplements individual and group supervision. Continuing supervision identifies and addresses intra-personal and interpersonal concerns related to accountability, limit and boundary setting, and transference and counter-transference issues. That is, volunteers learn their care-related functions in the clinical setting; the supervised practice of in-home support of caregivers who care for frail seniors makes each home visit a learning opportunity.

Fourth, Care Teams are created as a structured component that becomes a permanent feature of the congregation, which provides a stable basis for the team and a ready source for recruitment of additional team members. The sponsoring congregation accepts 'ownership' of the team, committing it to maintain and support its Care Team members and their services.

Fifth, encouragement of volunteer-based community services of religious groups, supported first by President Reagan and currently by President Bush, indicates the moment is ripe to propose this model. Opposition to Bush's proposal is based on questions of church-state separation. Location of the administrative functions necessary to support local initiatives in community-based programs ameliorates these concerns. Interfaith CarePartners is a free-standing 501[c]3 interfaith agency created to administer the Care Team program in Harris, Montgomery, and Fort Bend counties. The organization coordinates the services of 1,500 volunteers in 80 congregation-based Care Teams in the greater Houston area. A staff of seven professionals staffs each team's monthly meeting and acts as a referral agency to the city's social service and home health agencies, hospital discharge planners, and other services requesting in-home support for their clients. This countywide, centralized structure is proving more efficient and

economically feasible than the alternative of smaller, neighborhood-based groups of volunteers that must compete for funds and other resources. Moreover, referring agencies need call only one central office to place clients.

Other models, created with assistance from Interfaith CarePartners, have been developed in ten other cities. With assistance from Interfaith CarePartners, replication of the Care Team model in North Carolina is being facilitated by the Carolinas Medical Center in Charlotte, NC. This hospital system has 18 satellite centers in North and South Carolinas. A similar model has been initiated in Missouri. While much of the relevant literature focuses attention on the needs of frail seniors, parents of children faced with months of care for a child diagnosed with incurable cancer and other chronic and terminal illnesses could also benefit from volunteer-based in-home care. Indeed, while most attention has been given to the need of frail adults for in-home support, particularly respite care, families with frail children are just as urgently in need of support.

Family caregivers are overwhelmingly women, mainly adult daughters or spouses, whose duties often deprives them of the education or careers they were looking forward to after their children left the nest. This deprivation is just as onerous for mothers of chronically ill and severely impaired children. When children are born with congenital illnesses or impairments early in their parents' marriages and both partners have already embarked on their vocational choices, mothers may be forced to forgo employment because of their children's catastrophic needs and because families are unable to afford paid caregivers. Interfaith CarePartners has recognized this problem, and designed "Kid's Pals" Care Teams to provide the same level of support to these harried parents as the respite program designed for frail adults and their caregivers.

As the twentieth century opens, there is a narrow window of opportunity in which to design and implement the effective response the nation will need in its efforts to cope with a steadily rising number of seniors, many of whom will experience health crises for which communities are little prepared to respond. Congregations are strategically placed and structured—and are called by their nature as people of God—to provide leadership as these opportunities and challenges are confronted.

SUMMARY

The Hospital as a Resource to Congregation and Community

1. Hospitals, based on their departments of pastoral care, have the resources necessary to initiate and sustain a Care Team partnership linking hospital and congregations.
2. Chaplaincy staff, supported by ancillary staff from other departments, can train Care Team members with the range of skills needed to assist families with special needs.
3. Chaplaincy staff can provide continuing supervision of Care Team activities:
 - i. Staff may personally supervise teams;
 - ii. CPE students may supervise teams as aspects of their own training;
 - iii. Staff may oversee part-time personnel who supervise teams;
4. The hospital has the resources to provide the infrastructure necessary for the development and maintenance of the program.
5. By facilitating the timely discharge of patients to home support, the program also benefits the hospital by enabling it to provide services within the reimbursement limits and extends its services to outpatients.

In *Ministry to Outpatients*, I suggested that one of the tasks confronting chaplains is to ensure that patients are perceived as people whose location is not the hospital but the community. The following issues were raised:

- * Chaplains should invite patients' pastors and rabbis to view the hospital as the extension of their care of their own members. Congregational clergy fulfill a much more intensive pastoral function than chaplains can in their brief patient encounters.
- * Chaplains' priorities should include support of patients' congregations where most spiritual support is located.
- * The support of the patient's primary spiritual caregivers, lay and ordained, should be high on the chaplain's list of priorities.

Promotion of the Care Team program and development of partnerships with participating congregations can produce measurable benefits for healing institutions: Care Teams

- * serve the institution's interests by creating partnerships with congregations;
- * support out-patient care by recruiting lay teams which become an extension of the hospital's care of its patients.
- * enable congregations not only to serve their member families with special needs but to develop outreach programs which address the needs of families which lack congregational support;
- * improve in-home support for patients following discharge from hospital;
- * ease patients' anxieties over early discharge from hospital as a consequence of dependence on managed care programs.