Unmet Need for Chronic Disease and End-of-Life Care at Urban Family Health Centers in the Bronx, NY

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Background and Objectives: With population demographic shifts and as people live longer with progressive incurable illnesses, there will be a growing need for community-based chronic disease and end-of-life care services. Family practice sites could be strategic community-based settings in which to offer chronic disease and end-of-life care. This study determined whether two urban family health centers were meeting the chronic disease and end-of-life care needs of health center users, their families, and the local community. Methods: Using a brief structured interview instrument, we interviewed a convenience sample of 218 patients at two hospital-affiliated family health centers in the Bronx, NY, about their recent experiences with serious illness and death of immediate family members. In addition, we developed geographically defined medical service areas for each health center and compared the age distribution of residents of the geographic areas with that of actual health center users. Results: Of 218 health center users, 18% (n=39) had experienced the death of an immediate family member in the past year, of whom only 8% (n=3) stated that their family member had received end-of-life/chronic disease care at the health center, and only 23% (n=9) knew that their family member could have received such care. Of 26% (n=56) of study subjects who reported having an immediate family member who was currently seriously ill, 18% (n=10) stated that their family members were receiving care at the health center, and 23% (n=13) knew that their family members could have received such care. Eighty percent (n=174) of study subjects stated that they themselves would be interested in receiving end-of-life/chronic disease care at the health center in the event that they needed such care. The age distribution of health center users significantly differed from that of the residents of the geographically defined medical service areas, with an underrepresentation of people over the age of 75 among the health center users. Conclusions: We identified a potential unmet need for chronic disease and end-of-life care among families of health center users and the larger community served by two family health centers in the Bronx, NY. Despite the frequent occurrence of serious illness and recent death among close family members, relatively small proportions of these family members had received care at the health centers, and few actual users were aware that such services could be provided there. Moreover, there was a significant demographic mismatch in age distribution between health center users and the surrounding community. These findings signal an important opportunity for the discipline of family medicine and its training programs to define and respond to the chronic disease and end-of-life care needs of patients and their families in community-based settings.

The US health care system faces the challenge of meeting the needs of an increasingly large population of older and seriously ill adults who do not die suddenly but rather die after a prolonged period of chronic illness. Over the course of a progressive, incurable illness, patients often need pain relief and symptom control, spiritual and psychosocial support, and comprehensive chronic disease management. Unfortunately, however, many patients with progressive diseases are either not offered these services or are offered these interventions too late to have a significant influence on their care and quality of life. As a result, the quality and availability of end-of-life and chronic disease care have been found to be deficient in many respects, particularly in community-based settings.

In primary care settings, advance care directives and advance care planning—key elements of a comprehensive approach to chronic, progressive illness—have been found to be inconsistently initiated. While these issues may be addressed late in the course of illness,
patients prefer early discussion of treatment options,\(^5\) and many patients with severe incurable illnesses prefer a course of care focused on providing comfort rather than prolonging life.\(^6\)

Family practice sites are appealing community-based settings in which to offer comprehensive evaluation and interventions for patients with chronic illness and for the elderly in general.\(^9\) With their patient-centered approach, family physicians are accustomed to involving patients and families in treatment decisions. Because they are familiar with their patients’ and families’ values, they are able to support patients and families through a complex set of treatment-related decisions.\(^12\) Further, family physicians are in a position to address the influence of illness within families, an area that has begun to be appreciated in the medical literature.\(^14\) Family physicians are also accustomed to working with a multidisciplinary team, making them well suited to coordinate what is often a complicated mix of specialty involvement in the management of progressive, incurable illness.\(^12\) Finally, in addition to working with other disciplines, family physicians have experience with a wide range of treatment modalities, making them poised to offer comprehensive care for serious illness.\(^14\) Thus, not only is family medicine well situated to offer patients and their families palliative and end-of-life care, it is also an ideal discipline in which to provide physicians with the knowledge, skills, and training particular to this area of care.\(^14\)

To date, however, there is little published literature investigating family physicians’ involvement in meeting the chronic disease and end-of-life care needs of elderly and/or chronically ill adults. Suspecting that there were unmet needs for chronic disease and end-of-life care among community-dwelling older adults within many communities, we interviewed patients at two urban family health centers about their experiences with serious illness and death in their families and about their perceptions of service availability for these needs. To assess whether these clinics reach older populations, which are most likely to need chronic disease and end-of-life care, we also assessed the age distribution of the communities served by the health centers and compared this distribution with that of the health center users.

Methods

Setting

This study took place between June 2000 and November 2001 at two family health centers operated by the Montefiore Medical Center Ambulatory Care Network in the Bronx, NY. Montefiore Medical Center is a large teaching hospital (1,100 beds) with a large outpatient network of primary and specialty care sites throughout the Bronx. The Ambulatory Care Network is comprised of nine sites that generate more than 286,000 patient visits per year. The network provides care to an urban underserved population with a high proportion of racial and ethnic minorities, primarily African Americans and Latinos.

One family health center (Site A) is located in the Fordham area of the Bronx, about 1 mile south of the main hospital. The patient population is comprised of about 50% Medicaid recipients, 15% covered by other forms of health insurance, and 35% self-pay/medically indigent. The major ethnic groups represented in this patient population are Latino and African American. There are also Southeast Asian immigrants from Cambodia and Vietnam and working-class whites of many ethnic backgrounds. The second family health center (Site B), located in the Castle Hill area of the Bronx, serves a patient population comprised of 24% Medicaid recipients, 40% managed care plans, and 13% self-pay/medically indigent. Similar to Site A, the major ethnic groups served by Site B are Latino and African American. In addition to their primary service role, both of these health centers are training sites for Montefiore’s family practice residency program.

Subjects

The protocol for subjects’ participation in this study was approved by Montefiore’s Institutional Review Board. A convenience sample of patients visiting the two health centers was used. Patients at the two family health centers were approached in waiting rooms by research assistants. Those who spoke Spanish exclusively and those under the age of 18 were excluded from the study.

The purpose of the interview was explained, confidentiality was ensured, and patients were invited to participate. Patients were informed that their participation was voluntary and that their decision to decline participation would in no way affect their care.

While we do not have data on the entire group of patients approached for this study, data for 100 patients approached shows a refusal rate of 19% (n=19). Leading reasons for refusal to participate were Spanish-speaking only (n=7), not interested/not in the mood (n=6), not wanting to talk about death (n=2), and not wanting to participate in a survey (n=2).

Interview

Interviews were conducted using a brief standardized instrument and took place in a private room. Patients who chose to participate were asked to provide information about immediate family members with current, serious, life-threatening illnesses and about family members who had died during the previous year. Study participants were also asked whether they were aware that chronic disease and end-of-life care were available at the health centers.

The focus of these questions was on immediate family members, defined as parents, siblings, or grandparents. Questions centered on whether the family mem-
ber had received care at the health center, whether or not subjects were satisfied with the level of care their family members had received (yes/no), and whether they had been aware that their family members could have received chronic disease and end-of-life care at the health center. In addition, study subjects were asked whether they themselves would be interested in receiving chronic disease and end-of-life care at the family health center if they were to need this type of care in the future.

Subject Demographics
Demographic information for the study sample was provided by study subjects. Subjects were asked to identify their age, race, and gender. Demographic profiles of health center users were compiled using clinical information available in Montefiore's centralized billing system, including all patients who made visits to the centers during the year 2001.

Data Analysis
To assess the proportion of elderly served by the health center relative to the proportion of elderly in the surrounding community, we devised a method to create a geographic representation of health center users. Using health center billing information to determine how many health center users resided within a given census tract, and using US Census 2000 data to determine the overall population within a given census tract, we calculated the proportion of residents who were health center users within a given census tract. For each health center, the census tracts were placed in order from highest to lowest proportion of health center users as a proportion of the total population residing within a census tract, and the mean proportion of health center users to the total population within a census tract was calculated. Those census tracts for which the proportion of health center users was greater than or equal to one standard deviation (SD) above the mean proportion were considered to fall within the medical service area of a given health center. Once the census tracts comprising the medical service area were identified, we determined the age distribution within the area using 2000 US Census data. The individuals captured in this data are, therefore, ones that live within a defined geographical area from which users of the center are likely to come.

Descriptive statistics for the aggregate data were calculated using SPSS Version 10.0. A goodness-of-fit chi-square test was used to determine whether there was a significant difference in age composition of health center users compared to the general population living in the surrounding communities within the defined medical service areas. Fisher exact test was used for comparison of proportions with cells less than five. To provide a better visual representation of the difference in proportions, a log transformation was used (Figures 1 and 2).

Results
Overall, 218 health center users participated in the study. Participants were primarily female, Catholic, high school graduates, and unmarried (Table 1). Nearly half of the study subjects were Latino (49.6%), and 40.4% were African American. Medicaid and Medicare accounted for the payment source of nearly 45.5% of the participants, while 17.0% were uninsured. The mean age of participants was 40 years (range 18 to 76).

The study sample was largely representative of the clinic population at both sites. Gender composition of study participants was similar to that of the clinic population (Site A: P=.47, Site B: P=.54). There was a non-

| Table 1 |
|---|---|---|
| Patient Demographics* | Mean | SD |
| Age, years | 39.94 | 13.77 |
| Greater than 65 years old | n | % |
| Gender | | |
| Female | 168 | 77.1 |
| Male | 49 | 22.5 |
| Marital status | | |
| Married | 85 | 39.0 |
| Separated/divorced | 20 | 9.2 |
| Widowed | 6 | 2.8 |
| Single | 106 | 48.6 |
| Race | | |
| Latino | 108 | 49.6 |
| African American | 88 | 40.4 |
| Asian | 9 | 4.1 |
| Other | 13 | 5.9 |
| Education | | |
| Elementary | 28 | 12.8 |
| High school | 146 | 67.0 |
| Junior college or above | 42 | 19.3 |
| Religion | | |
| Catholic | 169 | 77.5 |
| Other | 30 | 14.3 |
| None | 18 | 8.3 |
| Insurance | | |
| Private | 75 | 34.4 |
| Medicaid | 69 | 31.7 |
| Not insured | 37 | 17.0 |
| Medicare | 30 | 13.8 |
| Have regular doctor | 188 | 86.2 |

* n=218
SD—standard deviation
significant trend toward study participants being younger than the overall population of health center users (Site A: \(\chi^2=7.60, P=.11\); Site B: \(\chi^2=9.0, P=.06\)). At Site A, there was also a nonsignificant trend toward a different racial/ethnic distribution between the study population and the health center population (\(\chi^2=9.124, P=.058\)); there were more African Americans in the study population than in the health center population (43.4% versus 30.9%, \(P=.07\)), fewer whites (6.6% versus 16.0%, \(P=.03\)), and fewer categorized as “other” (0% versus 6.7%, \(P=.01\)). At Site B, the racial/ethnic distribution of the study population differed more significantly from that of the health center population (\(\chi^2=80.07, P=.00\)); there were more African Americans in the study population than in the health center population (38.7% versus 26.2%, \(P=.02\)), more Asians (4.2% versus 3%, \(P=.00\)), and fewer categorized as “other” (2.8% versus 12.2%, \(P=.00\)).

Users of the health centers tended to be younger than residents of the medical service areas for both centers (Figure 1, Figure 2). Differences in age composition were statistically significant for both sites: (Site A: \(\chi^2=440.6, df=5, P<.001\); Site B: \(\chi^2=181.2 df=5, P<.001\)). At Site A, the proportion of elderly community residents (>75 years) was almost three times greater than that of health center users (4.4% and 1.6%, respectively). The proportion of Site B’s residents in the geographically defined community who were 75 years of age or older was twice that of the actual users of the health center (4.1% and 2.1%, respectively).

Prevalence of Serious Illness in Family Members

Of 218 participants at the family health centers, 39 (17.9%) had experienced the death of an immediate family member the year before. Of those immediate family members who had died within the last year, participants reported that nine (25.1%) had died of liver disease, seven (17.9%) of cancer, five (12.8%) of diseases of the heart, three (7.8%) of external causes (such as homicides and motor vehicle accidents), three (7.8%) of old age, two (5.2%) of complications of kidney disease, one (2.6%) of cerebrovascular disease, one (2.6%) of AIDS, and eight (20.5%) of unknown causes.

Overall, 56 of the 218 participants (25.7%) had an immediate family member who was currently seriously ill with one or more chronic life-threatening diseases. Study participants stated that 15 (26.8%) of these currently seriously ill family members suffered from cancer, 13 (23.2%) from diabetes, 11 (19.6%) from diseases of the heart, seven (12.5%) from HIV/AIDS, three (5.4%) from cerebrovascular disease, and 14 (25.0%) of other chronic incurable illnesses.

Use of the Family Health Centers

Of 39 study subjects experiencing the death of a family member within the last year, only three (7.6%) reported that their family member had received care at the family health center. Nine (23.1%) study participants knew that the center offered chronic disease and end-of-life care.
Of 56 study subjects with currently seriously ill family members, 10 (17.9%) reported that their family members were receiving care at the family health center. Thirteen (23.2%) of the study subjects with currently seriously ill family members knew that their loved ones could receive chronic disease and end-of-life care at the center.

Study participants whose family members had received or were currently receiving care at the health centers reported satisfaction in all of the 13 cases. A total of 174 (79.8%) study participants stated that they would be interested in receiving chronic disease and end-of-life care at the center in the event that they needed such care themselves.

Discussion

This study reveals a potentially important unmet need for chronic disease and end-of-life care at two family health centers in the Bronx, NY. Health center users reported both substantial numbers of seriously ill family members and a high burden of death within their immediate families during the previous year. However, only a small percentage of these seriously ill and dying family members had actually received care at the health centers. Of these, all respondents reported being satisfied with the care their family member had received. In addition to reporting the potential unmet need among their family members, health center users were generally unsure that chronic disease/end-of-life care was available at the health centers and also expressed a strong hypothetical interest in such care if it were to become necessary. While the data from our study cannot address the key question as to why seriously ill and dying family members did not obtain end-of-life/chronic disease care available at the family health centers, the results raise the need to explore why extended family members in urban, underserved communities may not be receiving end-of-life/chronic disease care at family health centers.

Most patients with currently ill or recently deceased family members were not aware that their family members could have received end-of-life/chronic disease care at the health center. This finding is indicative of a missed opportunity to provide education about chronic disease/end-of-life care in the community. While reasons for the low awareness of the availability of chronic disease and end-of-life care found in this study were not within the scope of this investigation, it is possible that the high prevalence of young women and children common to family practice sites may discourage patients from believing that these sites offer care for seriously ill and elderly patients. In a similar vein, because many family physicians tend to see relatively young populations, they may not think of themselves as being in a key position to provide care for seriously ill and elderly patients.

If patients were more aware that chronic disease and end-of-life care was available from family physicians, it might be possible to expand services to the seriously ill and dying family members living in the area. While there is some anecdotal evidence from this study (data not shown) that seriously ill and recently deceased family members did not receive care at the health centers because they did not live nearby, further investigation into why family members with serious, life-threatening illness do not receive care at the health centers is needed.

The existence of an unmet need for end-of-life care as expressed by users of family health centers is consistent with a significant underrepresentation of elderly among users of the health centers as compared to residents of the surrounding communities. This difference is even more striking when one considers that since older adults tend to be heavier users of the health care system, they would be expected to be overrepresented in health centers. Further, because our community data and the definition of the medical service area is based on areas where users of the health centers live, it is possible that these data may be underrepresenting the true prevalence of elderly in the local geographic community. It is, therefore, possible that even more elderly live in the surrounding communities than is reflected in this data, which would make the mismatch even larger than what is presented here. This possibility is indeed likely given the higher proportion of residents over the age of 65 in the Bronx (10.4%, n=1,338,750) than in our two medical service areas (5.4% and 5.1%).

The demographic mismatch between users of the health center and residents in the community identified in this study is consistent with the recent literature. Lindbloom et al used geographic coding, telephone interviews, and chart reviews to study utilization of a community health center among older adults in Boone County, Mo. The researchers found that most poor older adults had not been served by the community health center. This demographic mismatch is consistent with documented literature noting the tendency for family physicians to see younger, less disease-burdened patients than other disciplines. While in some settings there may be financial disincentives for Medicare recipients, at our practice sites these sources of medical insurance are routinely accepted and welcomed.

Implications for Education

Since this study was conducted at two residency training sites, the lack of use of the health centers for end-of-life care represents not only a missed opportunity to provide chronic disease and end-of-life care but also a missed teaching opportunity. At the time our study was conducted, there was no special emphasis on chronic disease and end-of-life care training for residents at
these sites. In a study conducted at the same medical center, graduating third-year family practice, internal medicine, and pediatrics residents reported caring for few community-based patients at the end of life. \cite{10}

Residents reported caring for a median of only one outpatient who died and three outpatients who were terminally ill over their entire 3 years of training. Currently, we are in the process of developing a longitudinal palliative care component for residency training at the health centers.

Conclusions

The results of this study point to the opportunity to meet chronic disease and end-of-life care needs through family medicine and other primary care disciplines, an opportunity that is especially high in economically disadvantaged populations where mortality rates are high.\cite{9, 30} The focal point of this study, the Bronx, had higher age-adjusted disease-specific mortality rates than peer counties and higher than the national average for four of five major causes of death.\cite{22}

In view of the unique position that family medicine holds as a discipline committed to patient-centered, coordinated care, family medicine has both the strategic opportunity and responsibility to meet the end-of-life/chronic disease care needs of its patients, families, and community. To meet the growing chronic disease and end-of-life care needs of our specialty, concurrent attention to education and training in chronic disease and end-of-life care should be a key priority for family medicine in the years ahead.\cite{20, 21}

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