A Practice-Based Information System for Multi-Disciplinary Care of Chronically Ill Patients: What Information Do We Need?

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Primary care physicians provide longitudinal care for chronically ill individuals in concert with many other comunity-based disciplines. The care management of these individuals requires data not traditionally collected during the care of well, or acutely ill individuals. These data not only concern the patient, in the form of patient functional status, mental status and affect, but also pertain to the caregiver, home environment, and the formal community health and social service system. The goal of the Community Care Coordination Network is to build a primary care-based information system to share patient data and communicate patient related information among the community-based multi-disciplinary teams. One objective of the Community Care Coordination Network is to create a Community Care Database for chronically ill individuals by identifing those data elements necessary for efficient multi-disciplinary care.

INTRODUCTION

Approximately 35 million Americans have chronic severe disability, and more than 9 million Americans are unable to perform a major activity of daily living, disproportionately affecting low income and elderly individuals [1,2]. Historically the acute care hospital has been the focus of health care for chronically ill patients and the traditional medical record has served as a repository for patient data as well as provided for continuity of care and exchange of information among the many participating disciplines [3]. Shorter hospital stays have resulted in patients returning to the community earlier in the course of illness and resulted in the provision of many health care and support services to the community. Furthermore, many individuals with disabling chronic diseases are able to maintain independent community living only with the assistance of community health care and social service agencies. Some patients may even require care or services from several agencies, and the number, intensity, and types of service may vary over time.

Most communities have developed an array of community-based health care and social services such as in-home professional services, personal care services, transportation, adult day care and respite care. These services are often highly fragmented with many service providers operating a number of different programs with varying eligibility criteria. Information systems to provide accessible patient clinical data and expedite information exchange, analogous to the traditional medical record, have not kept pace with the development of community-based health and social services. In addition, the current health care delivery system does not promote the routine collection of patient and caregiver psychosocial data to support the delivery of formal and informal health and social services to chronically ill individuals. Even when community-wide information systems have been implemented by social service agencies to help coordinate community-based services [4], the information system cannot be used to identify patients in need of services, but only serve patients who have been referred by health care providers. Finally, social service-based systems may not be designed to facilitate communication between agencies and the primary care providers.

The primary care physician must play a critical role in development and application of innovative information systems to facilitate the timely, effective and efficient delivery of these services to chronically patients living in the community [2]. The primary care physician participates in all levels of care: identifying chronic conditions which lead to impairment and disability; maintaining contact with chronically ill and disabled

patients as they move through the continuum of care; deciding about the need for hospitalization; authorizing almost all formal home and community care services. Therefore, the primary care physician is particularly well positioned to actively participate in the development and use of community-based health and community service information systems.

Clinical management computer systems have been developed and implemented within some primary care practices for tracking both chronic illness and preventive care procedures [3-7]. These systems may also be an effective tool for the primary care physician to improve the care of chronically ill and disabled patients. The Community Care Coordination Network (CCCN), a project funded by the Robert Wood Johnson Foundation, will use such an existing clinical information system at Reynolds Health Center (RHC), a large urban community health center, to link health center primary care providers, community service providers and hospital personnel.

Two interventions within the CCCN will be studied in a factorial design, randomized, controlled trial. One intervention is the development of a network-based "Community Care Alert" which will serve to identify patients whose functional status and needs may have changed by "alerting" providers to the occurrence of sentinel diagnoses or health care events, such as emergency department visits or hospitalizations. This "alert" is intended to mobilize members of a multi-disciplinary team to address patient needs in response to changes in health and functional status. The other CCCN intervention is the development of a community care database, containing data necessary for multi-disciplinary, inter-agency care coordination. The database will target patient, caregiver and health care system factors which have been shown to influence health care and community service delivery as well as patient quality of life and caregiver burden. Secure off-site access to the database from the two acute care hospitals and the limited number of participating community health and service providers will be available using a dial-in, dial-back process. Eligible patients must consent to participate in the CCCN study, and agree to release health care data to the hospitals and agencies participating in the CCCN.

A goal of the CCCN is to reduce the rates of unmet community service needs, unnecessary emergency department visits, hospitalization, total health care costs. A more important goal is to improve patient and caregiver quality of life. The project is in the first year, and we present the process of database development, and database elements included in the CCCN database.

METHODS

Setting and Population The Med/Track (Clinical Software Systems Inc., Hingham, MA) system implementation and data elements have been described in the past [7], copntaining data elements presented in Table 1. Mark-sense forms and optical scanning are currently employed for rapid, inexpensive data entry of encounter data at RHC, and will be employed for CCCN questionnaires and forms. To standardize data collection, trained interviewers will administer all patient questionaires. The caregiver questionaires will be self-administered. The CCCN data will be linked to the traditional patient files and displayed in supplemental user-defined datasets within the RHC clinical information system.

Table 1. "Traditional" data elements in the RHC database.

Patient Demographics
Primary Care Provider
Diagnoses
Medications
Allergies
Preventive Care
Visit History

The study population for the CCCN are one thousand chronically ill patients with functional impairments. Patients will be identified by searching the database (over 57,000 patient records) for patients with diagnoses associated with a high prevalence of functional impairment. Patients will be screened for deficits in activities of daily living (ADL) and instrumental activities of daily living (IADL); those with 3 or more IADL impairments or any ADL impairment will be eligible for the study.

Database Development Process Several strategies were employed to determine which data elements would be collected within the CCCN. First, the literature was reviewed for data elements which have been shown to be predictors of health service utilization, hospitalization, prolonged length of stay, or the need for community-based health or

586

social services. Next, a group of community-based health and service providers (physicians, nurses, hospital and agency social workers, home care administrators) gathered and analyzed the data collection instruments currently used by their agencies. The group determined that the bulk of information collected by agencies was required by third party payers for reimbursement, and the remainder supported the clinical care plan. There was a large degree of heterogeneity in format and content of currently collected information, both across agencies and among third party payers. The group suggested collecting information of clinical benefit in supporting multi-disciplinary care but not currently collected by agencies or required by third parties.

The group then reviewed a series of standardized data collection instruments derived from the literature, and chose instruments which reflected their data needs, and satisfied third party requirements. Previouly validated medical and psychosocial screening and data collection instruments were chosen for the CCCN database when available to accomplish data collection. When several data collection tools were possible (eg. depression screens), instruments specifically validated in the target population (chronically ill, predominantly elderly patients) were selected. Data elements duplicated in screens and instruments were removed. Finally the investigators added research-related and generic health quality measures necessary for analysis of the trial.

RESULTS

The CCCN database consists of a variety of data elements, organized into three general components: patient-centered data, caregiver data (ie. informal support) and professional and community service data (ie. formal support). Patient-centered data include a range of information about patients' physical function, cognitive function, sensory impairment, affect and personal health care decisions. These data represent a combination of standardized instruments and measures developed specifically for the CCCN. For example, a standardized assessment of the patient's ability to perform daily activities (OARS) will be supplemented by a more detailed assessment of the types of personal assistance and assistive devices used, as well as a patient assessment of the degree to which a daily activity need is met [8]. The Center for Epidemiologic Studies-Depression

Scale (CES-D) and nutritional screen [9] were incorporated because of the exceedingly high prevalence of depression among chronically ill individuals [1,10]. The short form of the Mini-Mental State Exam (MMSE) is included because cognitive impairment is a major determinant of the need for formal and informal community services, and a major source of caregiver stress [11]. Table 2 presents the patient-centered data elements.

Table 2. Patient-centered assessments in the CCCN database.

Functional Status (OARS)
Social Support
Cognitive Function (MMSE)
Depression Screen (CES-D)
Vision/Hearing Screens
Assistive Devices/Aids
Nutrition Screen
Home/Environmental Screen
Advanced Directives

The professional and community service data component provides detailed information not typically found in a medical record, but determined by the focus group to be important in the provision of appropriate community-based care This information includes a listing of the types of health and community services used (eg. Home Health, Meals on Wheels) the names, addresses and phone number of formal caregivers, and important hospital and pharmacy data. Table 3 presents the professional and community services data elements.

Table 3. Professional and community service data

Professional Services
  Hospital Discharge Plans
  Professional Care Plans
Personal Care Services
  Type
  Frequency
  Duration
Pharmacy Name and phone

The availability of information about the social support and informal caregiver status was

587

also identified by the focus group as extremely important in the care of chronically ill patients. The database will include extensive information about the extent of the patients' informal caregiving and social network, and will indicate risk factors for social isolation [12]. In addition, patient's primary caregiver data will include functional assessment, affect screen, and level of caregiver burden and stress; information which could help identify patient/caregiver pairs who need additional services. Table 4 presents the social support data elements.

In pilot testing, the interviewers required between one and one-half to two hous to complete the entire patient battery. The caregiver self-administered survey, at approximately a seventh grade reading level, required approximately 30 to 45 minutes to complete.

Table 4. Caregiver data elements in the CCCN database.

Demographics
Functional Assessment
Social Support
Perceived Need for Services
Self-reported Health Status
Depression Screen (CES-D)
Health Quality of Life (SF-36)
Caregiver Burden
Caregiver "Hassles" Index

DISCUSSION

The central hypothesis of the CCCN study is that a multi-disciplinary database, coupled with improved communication between community care personnel and primary care physicians may improve patient care outcomes and prevent unnecessary use of emergency services or hospital admission [13]. Even during exacerbations of illness when hospital services are needed, a community-based computer system could facilitate data exchange between hospital and health care and community service providers, assuring hospital personnel that needed post-discharge services and follow-up will be provided. Finally, a practice-based information system may aid physicians in identifying patients in need of services, match patients to available services [4], and reduce

duplication and fragmentation of health care and community services [14].

To alter the current health service utilization among chronically ill patients and improve patient and caregiver quality of life, Community Care Database must contain data which supports health and social service providers in addressing the needs of chronically ill, functionally impaired patients and their caregivers. These data are qualitatively distinct from the traditional medical database, and must focus less on diagnoses and medications and more on the functional impairment resulting from chronic illness, patient environment and social support and caregiver needs and social support. These data must detail, and indeed justify, the professional and physical resources necessary to maintain the individual in the community.

A major concern in designing the database is the use of widely accepted and validated instruments. For many home care agencies, data collection has been determined as much by the requirements for reimbursement as to support clinical decision-making. Thus, patient data collected by various agencies, although similar, is not directly comparable. Importantly, data comparability may facilitate the provision of services to individuals who may not otherwise be identified simply on the basis of functional status. For example, the needs of a functionally impaired individual living alone may be dramatically different from an individual with an extensive social support network. Nonetheless, the standardized instruments must satisfy agencies' financial reporting requirements to prevent duplicate data collection. The CCCN database attempts to address these requirements.

In order to generalize to the practice of health professionals in the community, the database content must reflect data of diagnostic or prognostic significance across the range of chronic disease diagnoses. Thus the CCCN database incorporates screening measures for important, high prevalence co-morbidities such as cognitive impairment and depression. However, the amount of time required to collect data must not be prohibitive so shortened instruments (GDS, MMSE) have been incorporated when available. A shortcoming of the database is the lack of an extensive assessment of patient health care preferences beyond the solicitation of advanced directives and health care power of attorney. The standardized collection of these data could have a significant impact on the primary CCCN outcome measures such as emergency room visits, hospital

readmissions, length of stay, and total health care charges.

The CCCN database includes extensive data on informal caregiving and on formal community services. One effort within the CCCN will be to relate these support systems in such a way that care managers in the CCCN may anticipate the formal service needs of patients in response to changes in patient or caregiver status [15]. Unfortunately, the CCCN cannot at present automatically link patient (care recipient) and caregiver health care data since many caregivers may receive primary care in other settings.

Finally non-medical outcome measures such as quality of life and life satisfaction must be incorporated into the CCCN database since traditional measures such as return to work, morbidity and mortality are not the most discriminating outcome measures in chronic disease management, and cannot measure effects of health and service provision on caregivers. In managing chronic illness, maintaining function, maximizing independence and preserving patient autonomy become the goals of treatment, and the multi-disciplinary team must work in concert to support these goals. The CCCN database potentially provides a common infrastructure from which to coordinate these efforts.

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