Community Care for People with Chronic Conditions: An Analysis of Nine Studies of Health and Social Service Utilization in Ontario

SUSAN WATT, GINA BROWNE,
AMIRAM GAFNI, et al.*

McMaster University, Ontario

INCREASINGLY, HEALTH CARE SYSTEMS ARE SEARCHING for more effective and less expensive ways of providing care. Systems that were initially designed to deliver acute care are now being called upon to treat the increasing numbers of people with chronic conditions. Paralleling the growth in chronic conditions is the rising popularity of deinstitutionalization (Frenk 1994). As governments and other insurers push to contain health care costs, and as technologies have emerged that enable them to do so, care is being transferred from institutions to the community (Laws 1989). In many locales, models of practice that were originally developed for institutional care have been shifted wholesale, and often without adequate resources, into the community (Welton, Kantner, and Katz 1997).

Institutional models of care assume the need for quick responses to acute symptoms of disease or trauma. Their focus is medical, they are designed for rapid intervention, and they treat the patient's unique and immediate medical situation within a particular institutional context. Therefore, although emergency-room, acute, and rehabilitative care, for example, all differ, they nevertheless share the common characteristic of

*Coauthors of the article are Jacqueline Roberts and Carolyn Byrne.

medically defined intervention: they all use the systems and resources of the hospital setting, which encompasses a concentration of high technology, intensively trained personnel, easy access to x-ray and laboratory services, a full range of hotel services, and a 24-hour operational schedule.

The acute-care model is ill equipped to respond to the combined issues of chronic situations and community care (Wagner, Austin, and Van Korff 1996; Lucas 1996). The new challenge for planners and providers of chronic care is to understand how its effectiveness compares not only to institutional care, but also to other forms of community care.

An alternative to the institutional model is a program of community care that focuses on individuals' health and abilities and is only secondarily concerned with minimizing or containing symptoms. Such proactive models in the health field largely originate in the work of public health experts (Coye, Foege, and Roper 1994), and they have been evaluated primarily for their ability to reduce the morbidity and mortality associated with specific illnesses (Hypertension Detection and Follow-up Program Cooperative Group 1979; Diabetes Complications and Control Trial Research Group 1993).

More recently, managed care arrangements have come into favor in the U.S. health market; however, they continue to rely on models that are basically medical (Ostry 1994) and driven by the economic imperative of cost reduction without quality loss (Luft and Greenlick 1996). Public health models, on the other hand, share with proactive treatment models an emphasis on the cause that precedes the symptoms (Nakanishi, Tatara, and Fujiwara 1996). Neither approach, however, completely addresses the presence of a chronic dysfunction of pathologic or mechanical origins for which there is no known cure or predictable resolution (Bickenbach 1993); nor does either one address the complex biopsychosocial issues faced by people with chronic problems. Both continue to view chronic situations as individual, discrete, and, ultimately, preventable, treatable, or containable. We are unaware of any published evidence to the effect that the use of acute care models of intervention in situations of chronicity results in effective, efficient care.

The variety of approaches to community care of chronically ill clients derives from different assumptions about the health care problem and its potential solutions. Some community-care initiatives adopt the medical perspective, which sees clients as suffering from discrete physical and/or mental impairments that are in need of repair. After the initial impairment is treated, however, often quality-of-life issues, such as the

client's social and economic circumstances, environment, personal health practices, and coping capacity are ignored (Evans, Barer, and Marmor 1994). Risk factors associated with traditional treatment approaches, like confinement, immobility, and isolation, often lead to further physical, mental, and emotional deterioration. Common coexisting problems, like chronic illness and poverty, intensify dependency, which may cause clients to use more health services in order to relieve distress and deal with the social issues that have become intertwined with their health difficulties (Thompson 1996).

Clinical practice models, the education of health care providers, and research initiatives have not kept pace either with the change of venue to community care or the recognition of the pressing need for care among people with complex chronic circumstances (Thompson 1996). In changing the location of care, the cost has often been shifted from insured services to out-of-pocket individual expenses. For example, in Ontario, medications provided in a hospital are free of direct charge to patients (i.e., they are covered by public insurance), but the same medications prescribed at home must be paid for out of the individual's pocket and may or may not be covered by private, extended health insurance or, depending on the person's age and economic circumstances, by any government program. In addition, practices that work efficiently in the hospital may be ineffective, inefficient—or even impossible—in the community. For example, a hospital routine of daily physiotherapy may be impossible to duplicate in the community. Even when the resources are available, often transportation is not, adding to the patient's financial burden. If the ongoing shift of disease patterns toward chronic conditions is to result in an accessible and affordable health care system, we must reassess what portion of it can be provided in the community and explore what works, for whom, and under what circumstances.

We will discuss the lessons that have emerged from nine community care studies of people with chronic conditions. We will analyze the findings of commonly located studies of different groups of subjects, rather than examining differently located groups of subjects with a common medical condition. We will document the relationship of chronicity, location, care systems, and research methodology among the nine studies. We believe that the findings of this type of qualitative analysis of quantitative studies are instructive for policy makers who wish to determine, across chronic conditions, but within a common health and social service delivery system, the most effective and efficient ways to provide

services to persons living in the community with chronic conditions. Policy planners thus will have the opportunity to examine how services are delivered, rather than looking only at the characteristics or specific health problems of individuals using the system.

We have observed that, regardless of patients' characteristics or conditions, certain *program characteristics* were associated with good outcomes, usually at a cost that was equal to—or even less than—the cost of the same care provided in an institution. The characteristics of the system also determined who bore the costs of care for chronic conditions in the community.

Examining Community Needs and Community Services

Against this backdrop of changing health care circumstances, a series of nine studies (five historic cohort and four randomized trials) was undertaken to evaluate programs of community care in southern Ontario for people suffering from a variety of chronic conditions (Emond and Browne 1992; Weir, Browne, Tunks, et al. 1992; Browne, Roberts, Watt, et al. 1994; Milne, Sacco, Cetinski, et al. 1994; Pallister, Browne, Roberts, et al. 1995; Byrne, Brown, Voorberg, et al. 1995; Roberts, Browne, Streiner, et al. 1995; Majumdar, Browne, Roberts, et al. 1996; Hay, Bell, Mills, et al. 1996). All patients used services from the same provincially defined and funded health and social service systems.

In each study, we examined both the expenditures for, and the outcomes of, the health and social services used by groups of different social circumstances with chronic health conditions. The first five studies examined existing service programs and the patients who either did or did not receive care from these services. In the four clinical trials, specific problem-solving interventions to improve clinical outcomes for patients were tried out.

In the four clinical trials, the interventions were designed according to D'Zurilla's model of problem solving (D'Zurilla 1986). In each case, the intervention was based on the same process: problem orientation; problem definition and formulation; generation of alternative solutions; decision making; implementing solutions; and verification. The goal of all interventions was to increase the individual's problem-solving competence (ability and performance) and his or her sense of personal control.

The interventions were customized to fit the individual and his or her concerns, rather than the concerns of the professional staff, and their goal was to help the individual generalize to other problematic life situations.

The original purpose of the studies was not to examine systemwide service issues. Indeed, each study was initiated with the intent of discovering whether or not a specific service was effective, for whom, and at what expense. In reviewing the results of these studies as a whole, some common themes on the effectiveness and cost efficiency of certain types of community care for particular kinds of clients began to emerge. Our research established that absolute expenditure for health and social services varies with the circumstances of the chronically ill client and not with the severity of the medical condition. Shaughnessy, Crisler, Schlenker, et al. (1997a) view both utilization and severity as outcomes, and they see utilization as a proxy for a negative change in health status. However, they note that the presumption cannot be made that home care services (i.e., services provided in the community) are proxy measures of severity. Thus, although most research has found a positive association between severity and utilization, there is a paucity of community-based research demonstrating a parallel relationship.

Each study had different samples and sample sizes but was drawn from a common population in southern Ontario. In eight of nine studies, equal or better outcomes at the same or lower cost were reported when clients used a program of services that anticipated need, rather than a collection of reactive services designed to respond to symptoms of distress.

All subjects were receiving care from publicly funded health services. Across studies, clients were assessed with outcome measures appropriate to their circumstances. Thus, not all studies shared outcome measures, but all outcome measures shared the characteristic of measuring changes in the subjects' health problem(s). All studies examined services provided in the community rather than institutional (inpatient) care.

Communities in Transition

In Ontario, medical services are reimbursed through a publicly funded, universal health insurance system. Services are primarily paid for by public insurance on a fee-for-service basis to private practitioners. Individuals have absolute choice in the selection of family practitioners, who, in turn, are allowed complete control in choosing specialist services. Access to services is controlled by physicians, and family physicians control

access to specialist services. The insurer has no direct control over access to insured services, nor is there a cap on the amount of service or its cost. The decision about which services are provided is a clinical one. Waiting lists are the main mechanisms of access control. All in-hospital emergency, acute, and rehabilitative care is fully funded at no additional direct cost to the patient. Long-term care in hospitals or nursing homes is partially funded. A copayment system applies in long-term care.

In the community, in addition to medical services, prescription drugs, assistive equipment, and medical supplies are available, at a minimal out-of-pocket charge, to individuals who are 65 years of age and older or who are receiving public assistance. In Ontario, these drugs, supplies, and equipment are restricted by the Ministry of Health, which may consider specific requests, under exceptional circumstances, for coverage of a shrinking list of noninsured goods and services. For other people, these goods are provided as part of publicly insured services only in a hospital or under the HomeCare program, which was designed to reduce the length of inpatient acute care services by switching them to the home or, in the case of children with chronic medical conditions, to school during the school day. Private supplementary insurance, which is most often employment dependent, may also be a source of payments.

The increase in acuity of illness in the community, the reductions in length of stays in acute care hospitals, and the added, more burdensome, admission requirements for institutional long-term care have been accompanied by increases in the out-of-pocket expenses borne by the patient. Community programs are being strained by demands for their services. Health care in Ontario is moving out of hospitals and into the community; as it does this, the costs are being transferred from public insurance to individual patients, private insurers, and to both the local and the provincial social service systems. Veterans and their families continue to be assisted by a federal program, which enables them to purchase health and social services and thus to remain in the community.

Social services for the general public, on the other hand, are generally selective. The availability of community-based social services, with the exception of mandated child welfare services, depends largely on the financial need of the client. Similarly, social services are being pressed to decrease expenditure, demonstrate efficacy, and reduce eligibility.

Traditionally, institutional health services have had personal social services attached to both their inpatient and outpatient programs. Home-Care funds personal social services on a limited basis for its clients, but

provision of these services is determined by the individual's economic status and need for health services.

The voluntary health sector provides some individual and group counseling related to particular conditions on an income-based, sliding-fee schedule. It also offers a variety of supplies, equipment, meals, and transportation for specific, often disease-defined, subgroups. Most social services have significant waiting periods, even after eligibility has been established. The combined impact of higher demand and dwindling resources is restricting access to both institutional and community-based social services. People in Canada generally view health services as an entitlement that is fully paid for through provincial insurance. In short, they expect to get what they need, when they need it, at no additional cost to themselves. Increasingly, they are frustrated in their expectations.

Community Chronic Care Research

Much of the research on community-based services for the chronically ill examines patterns of care in the community. For example, studies have compared the role of the nurse in a hospital and in the community. We were unable to locate published accounts of any systematic, standardized studies of expenditures and outcomes for alternative programs of community service interventions in a publicly funded system of health care. We began to recognize that, without comparisons across studies, samples, and settings, it is difficult to arrive at any meaningful conclusions about which strategies of community care best serve various categories of clients most effectively and efficiently.

The published literature on long-term care has compared the expenditures and effects of community care of chronically ill clients with institutional treatment and ongoing management (Kane 1986). Less is known about how alternative community programs for chronic conditions handle these factors in the context of universal, publicly funded insurance and selective social service programs.

The case mix literature is only beginning to address the issues of chronic conditions and community-based care. Shaughnessy, Crisler, Schlenker, et al. (1997b) have since published their findings on case mix in home health care; these focus primarily on three types of outcome (pure, instrumental, and proxy) and their application as aggregate agency measures over time. Most of the case-mix literature focuses on acute and/or institutionally based care and excludes social services in the

analysis of utilization. Hence it is only marginally helpful as a basis for understanding chronically ill, community-based groups. Case-mix literature related to social services is in its infancy and is not helpful at this time for studying these issues. Therefore, as we began to build a body of work on community-based care of people with chronic conditions, it became clear that we had to reconsider our findings in a different way.

In trying to understand the results of each study, it became apparent that subgroups existed in each study sample that were related both to outcomes and to expenditures. It was equally evident that the relation between these variables (i.e., outcomes and expenses) was not always a main overall effect and that expenses did not, in these instances, serve as a proxy outcome. In short, increased expenditure did not always result in, or reflect, better outcomes, and, concomitantly, decreased expenditures did not result in, or reflect, poorer outcomes in each sample. These findings led us to ask the more complex question, "What works, for whom, under what conditions, at what cost, borne by whom?"

To examine this more complex question, we began to compare our results across studies of different programs, to use comparable measures, and to examine a wider range of clients' biopsychosocial characteristics as well as program orientations and interventions. We wanted to be able to identify the group(s) for which a particular program with a particular mix of health and social services would provide benefit(s).

Transferring Care; Shifting Costs

This type of comprehensive vantage point is often ignored in financial analyses of community health care services. The transfer of costs between the health and social service sectors is lost to individual program or service evaluation. Although the nine studies were conducted in southern Ontario, they reflect similar community service options (single-system universal health care coverage; multiple selective social service; uncoordinated health and social services) and client circumstances (downloading of care; increased emphasis on client self-care and out-of-pocket expenditures), which are often encountered in other community-based, tertiary (academic) centers. In essence, we have come to appreciate that there may be a direct symbiotic relationship between the health and social service systems, just as there is between the social and physical well-being of the individual. If people do not find answers to their difficulties in one system, they search in another for assistance.

Up to this point in Ontario, programs have been primarily oriented to medical conditions, with little attention to client circumstances. Simply put, programs have been developed that treat diseases and are not necessarily directed toward the needs of people. Payment is based on diagnosis. Lengths of hospital stays are built on diagnostic averages unmitigated by patient circumstances. By extension, reductions in service have tended to be “across the board,” rather than targeting groups that would experience the least negative impact as a result.

For example, caps on hip replacement surgery have been based on the cost of the mechanical replacement hip to the hospital where the procedure is performed. The cost of the replacement hip is borne by the global budget of the hospital, and it competes with other budgetary items. This strategy is based on the argument that individual surgeons are in the best position to determine the relative urgency of the need for the replacement. Thus, waiting lists were based on relative medical severity rather than on other factors, like the degree of disability and its impact on the individual’s life—perhaps most critically on his or her ability to work. Failure to spend health care dollars on a hip replacement may result in increased expenditures in the social service sector for income replacement.

In the mental health arena, any reduction in inpatient care, especially for people with severe and chronic psychiatric conditions, has led directly to increases in homelessness and numbers of chronically socially disabled people living in poverty in urban centers. Historically, as we have measured it, psychiatric disability decreases and social disability increases. What remains the same is the total complement of people who are in serious psychic and social distress and who need services. Yet the total cost of health services, despite these cost-cutting measures, continues to increase, particularly for certain subgroups.

We may now be just beginning to understand why we can reduce service in one area but inadvertently increase total costs. This shift in costs between sectors may be particularly pronounced when access is reduced. Reducing access to one part of the system may simply increase use in other parts that are not necessarily less costly. Thus, for example, reductions in hospital costs may well result in increases in community-based costs. Health care costs may decrease, but social care costs may rise. It is even debatable that health care costs have decreased. In Ontario, at least, reductions in long-term-care facilities for people with chronic psychiatric illnesses have created a revolving acute psychiatric care system,

which essentially ignores the presence of chronic psychiatric illness and responds instead to what is being redefined as a “cyclical acute illness” or a failure of acute care. What we have not understood to date is the impact of changes in one part of the care system on other parts. We have tended, as researchers, analysts, and planners, to focus on one part at a time and to avoid the complex issues of whether, and how, the parts form a whole care system. This paper is an attempt to bridge some of the parts by exploring how people with a variety of chronic conditions make use of the resources in both the health and social service systems in an effort to relieve their distress.

We caution that, although these studies included people with a number of chronic conditions and various levels of dysfunction, all were able, with varying degrees of distress and difficulty, to live in the community. They received their care in the community and not in institutions. We have not compared our outcomes with groups whose chronic illnesses required in-hospital care, nor do we claim to have covered the full spectrum of chronic illnesses in these studies.

How We Examined Community Care: Study Methods and Results

A retrospective cohort design was used in Studies 1 to 5. Subjects who had been referred to specific comprehensive, client-centered community ambulatory services were categorized as awaiting, enrolled in, or declining these services. Subjects were assessed after a minimum of two months in a service category. Random allocation procedures were used in Studies 6 to 9, which controlled for the problems of self-selection and noncomparability of groups that may have occurred in Studies 1 to 5. A summary of the method used in the cohort studies is provided in table 1. A comparable summary is provided for the randomized clinical trials in table 2. A detailed description of the methodology and results of each can be found in the original reports.

In each of the prospective cohort studies, adjustment to chronic illness and overall well-being at one point in time was measured in a variety of ways. Factors such as the client's and/or caregiver's perceptions about his or her purpose in life, social support networks, caregiver burden, mental health of clients, adjustment to illness, and overall functional status were measured (table 3). The actual degree of improvement (change) in

adjustment and well-being also was measured in the randomized control trials (table 2). The details of each measure are summarized in table 4.

The five cohort studies assessed the effects and costs of integrated, client-centered community care for persons who were cognitively impaired, adults with mental health problems, patients referred to specialty pain clinics, patients who were in the aftermath of a stroke, and adolescents with mental health problems. In each case, the service was characterized by its focus on improving the problem-solving capacity of the individual through a custom-designed program of integrated health and social care that at once responded to the current health and social needs of the individual and anticipated future difficulties. The exact mix of services was tailored to each participating subject. The approach, rather than its execution, was standardized.

The prospective randomized trials allowed for more definitive conclusions about the most economical and efficient way to provide community health care for chronically ill people with varying characteristics. The use of a prospective design allowed for an estimation of change in client status over time. Any biases that may have been operative when clients self-selected to a particular service strategy were minimized by the use of such designs. Although problems of recall and/or client self-selection potentially threaten the validity of historic cohort analytic study findings, they tend to be far less costly than randomized trials and therefore will become more important as research resources decline.

The four randomized trials compared the effects and expense of different programs of community services for a variety of clients with those of the usual individually driven, medically oriented community care. Specifically, Study 6 compared the impact of a program that taught empowerment skills with the results of one that promoted individual health solely through lodging-home care. Study 7 tested the effect of a program of cultural sensitivity training for providers on the functional outcomes of their clients. In Study 7, proactive comprehensive treatment of seniors who were screened for high-risk factors was compared with reactive treatment of a similar group. In Study 9, people with chronic conditions and poor adjustment to their situation were randomly assigned to problem-solving counseling, telephone support, or medical care alone.

In eight studies, the comprehensive, integrated approach to care—that is, one that included a full range of health and social services—was associated with equal or better outcomes in terms of well-being, at the same or less expense, than were traditional approaches based on

TABLE 1
Methodologic Summary of Cohort Studies

Study design	Sample and size	User groups	Outcomes	Expenditures for all health services used per person per annum per group
1. Historic cohort (Milne <i>et al.</i> 1994)	Caregivers of cognitively impaired relatives referred for day program (N = 46 respondents of 64 referred)	Day program <ul style="list-style-type: none"> • Enrolled (N = 24) • Waiting (N = 14) • Refused (N = 8) • Deteriorated (N = 18) 	Groups similar <ul style="list-style-type: none"> • Purpose-in-life scores • Social support scores • Burden scores 	Enrollees in day program are less expensive: \$6,779 versus \$8,235
2. Historic cohort (Emond & Browne 1992)	Clients referred to mental health program (N = 55 respondents of 163 referred)	Mental health program <ul style="list-style-type: none"> • Enrolled (N = 11) • Completed (N = 14) • Rerouted (N = 12) • Not engaged (N = 18) 	Groups similar <ul style="list-style-type: none"> • Mental health (GHQ scores) 	Current and former enrollees in mental health program are less expensive: \$592 (± 1186) to \$1,777 (± 3270) versus \$13,621 (± 31871) for those not enrolled
3. Historic cohort (Weir <i>et al.</i> 1992)	Clients referred to pain clinic (N = 222 respondents of 531 referred)	Pain clinic program <ul style="list-style-type: none"> • Completed (N = 41) • Incomplete (N = 44) • Consult only (N = 80) 	Groups similar <ul style="list-style-type: none"> • Psychosocial adjustment (PAIS) scores 	Users of pain clinic services are less expensive: \$3,285 to \$3,801 versus

4. Historic cohort (Browne et al. 1994)	Clients referred to community stroke rehabilitation day program (N = 152 respondents of 255 referred)	<ul style="list-style-type: none"> • Nonusers (N = 57) • Received (completed) (N = 19) • Enrolled in MCSS stimulation program (N = 26) • Enrolled in MOH physical rehabilitation program (N = 68) • Not enrolled (N = 34) • Institutionalized (N = 5) 	Rehabilitation day program Users of service better in activities of daily living (ADLs)	\$6,008 Users are less expensive: \$1,792 to \$2,219 versus \$16,607
5. Historic cohort (Pallister et al. 1995)	Emotionally disturbed, hyperactive, and conduct-disordered adolescents (N = 97 of 144 referred)	<ul style="list-style-type: none"> • Cooperative school-based mental health program • Waiting (N = 4) • Enrolled (N = 13) • Graduated (N = 45) • Withdrew (N = 13) • Rerouted (N = 22) 	Enrollees in the acute phase are better behaved and less distressed	Adolescents waiting for the program consume \$10,292 (\$±7635) in services versus enrollees, who consume \$5,520 (\$±649) per person per annum

Abbreviations: GHQ, General Health Questionnaire; MCSS, Ministry of Community and Social Services; MOH, Ministry of Health.
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TABLE 2
Methodologic Summary of Randomized Trials

Study design	Sample and size	Comparison group	Trial's effects and dollars of expenditures
6. Byrne et al. 1995	Psychiatrically ill residents of 21 lodging homes (N = 87 of 214 residents in 21 sites)	Programs of lodging-home care with <ul style="list-style-type: none"> • Empowerment (N = 24) • Health promotion (N = 25) • Lodging-home care alone (N = 38) 	Health promotion education resulted in 11% to 20% gains in resident quality of life with a \$3,500 greater per person annual expenditure if the resident reported a life low in satisfaction, low in hope for future, and an early onset of psychiatric illness.
7. Majumdar et al. 1996	Sixty-eight clients of 87 home and hospital providers	Provider training <ul style="list-style-type: none"> • With culture-sensitive training (N = 43) • Without culture-sensitive training (N = 44) 	Clients who received care from providers evidencing greater cultural sensitivity demonstrated improved functional capacity 1½ years later.
8. Hay et al. 1996	Ambulatory elderly >65 years attending a health service organization	Seniors who screened positive and were: <ul style="list-style-type: none"> • Proactively treated (N = 77) • Not treated (N = 86) 	Proactive screening, case finding, and treatment resulted in 11% to 22% gains in social and emotional function for seniors ≥75 years who lived alone and used \$2,019 per person/annum dollars of service, compared

9. Roberts et al. 1995	Poorly adjusted chronically ill medical outpatients of 1 of 27 specialty clinics (N = 293 of 490 randomized and completed follow-up)	<p>Augmented medical care with:</p> <ul style="list-style-type: none"> • Problem-solving counseling (N = 98) • Telephone support (N = 97) • Medical care alone (N = 97) 	<p>with similar seniors left untreated who used \$7,645 per person per annum of services.</p> <p>Persons receiving counseling who lived alone and scored low in problem-solving coping methods at baseline improved adjustment most at \$4,000 per person per annum compared with controls, who improved half as much and used \$40,000 per person per annum in services.</p>
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TABLE 3
Outcome Measures Used in Nine Studies

Study	Outcome measures	Outcomes measured
1.	Crumbaugh 1968 Weinert 1987 Zarit et al. 1986 Browne et al. 1990	Purpose in life Personal resources Caregiver burden Services used; cost of services
2.	Browne et al. 1990	Services used; cost of services
3.	Broadhead et al. 1988 Derogatis & Lopez 1983 Browne et al. 1990	Functional support Psychosocial adjustment to illness Services used; cost of services
4.	Zarit et al. 1986 Goldberg & Hillier 1979 Browne et al. 1992 Browne et al. 1990	Caregiver burden General Health Questionnaire Resources and services available Services used; cost of services
5.	Offord et al. 1987 Browne et al. 1990	Children's diagnostic instrument Services used; cost of services
6.	Lehman 1988 Browne et al. 1990	Quality of life in eight domains Services used; cost of services
7.	Browne et al. 1992 Browne et al. 1990	Resources and services available Services used; cost of services
8.	Broadhead et al. 1988 Browne et al. 1992 Crumbaugh 1968 Browne et al. 1990	Functional support Resources and services available and used Purpose in life Services used; cost of services
9.	Crumbaugh 1968 Broadhead et al. 1988 Derogatis & Lopez 1983 Browne et al. 1990	Purpose in life Functional support Psychosocial adjustment to illness Services used; cost of services

individual needs and on models of acute medical care. One study found improved well-being at greater expense (Byrne et al. 1995).

Programmed services were provided, based on a comprehensive assessment of the needs of the client, including medical, nursing, therapies, and social and occupational support. Transportation and recreation, as well as augmented homemaking and personal care, were included in the range of programmatic care. Although funded through health services,

TABLE 4
Outcome Measures Used in Nine Studies

Outcome measures	Description	Reliability
Crumbaugh 1968 Purpose in Life Questionnaire	Twenty items Seven-point scale ● High purpose ● Indecisive ● Low purpose	Split-half $r = .85$ to $.92$ Test-retest $r = .68$ to $.83$
Weinert 1987 Personal Resources Questionnaire	Twenty-five items Seven-point scale	Test-retest $r = .72$
Broadhead et al. 1988 Duke-UNC Functional Support Questionnaire	Eight items Two-point scale	Test-retest $r = .62$ to $.64$
Zarit et al. 1986 Caregiver Burden Questionnaire	Twenty-two items Five-point scale	Test-retest $r = .71$ $\alpha = .88$
Goldberg & Hillier 1979 General Health Questionnaire	Sixty items Two-point scale	$r = .95$
Derogatis & Lopez 1983 Psychosocial Adjustment to Illness Scale	Forty-six items Four-point scale	Interrater $r = .86$ $\alpha = .81$
Browne et al. 1992 (modified from Fillenbaum 1988) Older American Resource and Services Questionnaire: Part A	Functional capacity ● Social ● Emotional ● Physical ● Economic	Interrater $r = .67$ to $.89$
Offord et al. 1987 Survey Diagnostic Instrument	Three-point scale	$\alpha = \geq .74$ $r = \geq .65$
Lehman 1988 Quality-of Life-Measure	One hundred and forty-three items Seven-point scale in eight life domains: living situation, family, social relations, leisure, work, finances, safety, health	Relative value $\alpha = .79$ to $.88$ Test-retest $r = .65$ to $.72$
Browne et al. 1990 Health and Social Services Utilization Inventory	Interval scale	$r = .72$ to $.99$

social services were provided on a universal rather than a selective basis. This “package of services,” whose contents varied among patients and programs, had at its base the provision of a comprehensive set of services constructed on patient need rather than patient diagnosis, an approach that has been defined for the purpose of these studies as “programmed services.” Patients who were not part of a programmed service approach often accessed similar services but did so piecemeal, in response to specific problems and through the regular mechanisms for accessing care. No systematic coordination of their care was attempted beyond that provided by individual practitioners in response to individual problems.

In the historic cohort studies, people who never used the programmed services, and those who started the programs but withdrew before completing them, did as well as service recipients (Weir et al. 1992; Pallister et al. 1995; Byrne et al. 1995; Roberts et al. 1995; Majumdar et al. 1996; Hay et al. 1996). However, fragmented services were more expensive than complete programmed services. The group that received and completed programmed services did at least as well, *and at less cost*, than subjects who either did not receive such services or prematurely discontinued them (see table 5). Overall, people who were not enrolled in programmatic services used more medical services more often and with no better outcome, apparently drifting from less expensive health and social services to more expensive—but insured—medical services in an effort to relieve distress. In other words, where programmed services were available, there was a decrease in the use of more expensive, but no more effective, medical services.

Each study employed a standard method of utilization costing (Browne, Arpin, Corey, et al. 1990). In each study, potential cost “outliers” were identified, but they were not considered to be true outliers because they were found in all groups. Instead, groups were checked for homogeneity of variances and, when heterogeneity was found, variables were transformed through logs or nonparametric tests.

Policy Implications for the Design of Health and Social Services

In this era of cost containment and demand for fiscal restraint, health care systems are being pressed simultaneously to contain or reduce costs and to improve effectiveness. It has been argued that scarce resources can be

TABLE 5
Variables and Outcomes of Nine Studies

Program (enrolled; waiting; refused)	Clinical outcome measures	Clinical outcome (comparing groups)	Costs (per person)
Caregivers of cognitively impaired in day program	Purpose in life Social support Caregiver burden	Same	One-third less expensive
Clients in mental health program	Mental health	Same	Six times less expensive
Pain clinic program	Psychosocial adjustment	Same	One-half as expensive
Rehabilitation day program for stroke patients	Activities of daily living	Better outcome for users	Eight times less expensive
Cooperative school-based mental health program	Behavior and emotional distress	Better outcomes for subjects in program	One-half as expensive
Health education and empowerment training for psychiatrically ill lodging-home residents	Quality of life	Better outcomes with health education	Higher costs
Cultural sensitivity training for providers	Client reports of culturally sensitive services	Better outcomes with training (including increased functional capacity of clients)	Minimal increase for training costs only
Proactive treatment of screened seniors	Social and emotional functioning	Better outcomes for seniors 75 + when screened and treated	One-third the cost of unscreened and untreated persons
Counseling (problem-solving and telephone) with specialty medical care	Purpose in life Functional capacity	Subgroup of people living alone whose initially low problem-solving skills improved significantly	Subgroup 10 times less expensive with counseling

freed and allocated more appropriately than heretofore (Ontario Health Services Restructuring Commission 1997). Our analysis of nine studies suggests that resources can be better used to help people with chronic conditions through a commitment to coordinated, proactive programs of health and social services instead of conventional, reactive piecemeal community care. We think that planned and coordinated community-based care for people with chronic conditions, which targets the factors that determine health (Federal, Provincial, and Territorial Advisory Committee . . . 1994), will be more successful than services that are reactive, symptom-driven, and uncoordinated.

We found that health services are often substituted for other social or nonmedical services in a system that insures only health care. Our research suggests that high use of health services by persons with chronic illness is explained more readily by emotional, social, and attitudinal issues than by disease severity (Browne et al. 1990; Weir et al. 1992). Thus, high utilization of health services can be viewed as a type of help-seeking behavior that reflects the unmet health and social needs of chronically ill people.

A health promotion approach to community-based care is built on different assumptions (Terris 1992). Health promotion builds from the existing health status of the individual in an attempt to prevent further physical, social, and emotional deterioration. Under this perspective, providers adopt a more holistic approach than is characteristic of traditional medical interventions, enabling them to anticipate patients' needs and to figure out appropriate support services. A care system that is based on a health promotion perspective focuses on preventing multiple system decline and provides rehabilitation services and continued access to medical treatment as required. It builds on the strengths and capabilities of clients, empowering them to minimize the effect of risk factors associated with their limitations. It views the patient as an active participant in the process of becoming and staying well. It uses the full range of physical, social, and emotional supports to optimize functioning. Activities are guided and coordinated by the commitment to these goals instead of being driven by disconnected symptoms or isolated distress.

Our studies of clients who use these proactive community services (Browne, Roberts, Gafni, et al. 1995) show that they tend to have a lower frequency of health care visits, experience equal or better well-being outcomes, and accumulate lower overall costs. Hence, withdrawing such

comprehensive care is a false economy because efforts to do less to reduce face-value costs may actually cost more in the long run.

In addition to identifying the people who will benefit from comprehensive care, we must also find ways to ensure that clients complete programs. Contrary to popular wisdom, it seems that clients who leave community programs prematurely may do well; however, this improvement is achieved at an extraordinary cost to the health and social care systems. It is unclear how to go about retaining patients in a program of care; clearly this is a matter requiring further study. We also must determine which subgroups of people do well at the same or lower costs despite premature departure, so that we do not expend energy on retaining clients who would do as well elsewhere at a lower cost.

These nine studies also raise a number of important questions about the nature of community-based programs for chronically ill clients. Is the program truly oriented toward promoting the health of the individual? Does it define its target population proactively rather than waiting for clients to self-identify? Is it comprehensive and does it coordinate factors like social support, coping capacity, and personal health practices, which determine health, or is it merely a more comprehensive symptom- and disease-specific service? How does the program recruit and retain clients? How is the effectiveness of the program evaluated? Does the evaluation include measures not only of symptom reduction or containment but also of client well-being and the costs of achieving various effects? Does the evaluation track and follow up clients who prematurely withdraw from the program?

Second, it is important to adopt a comprehensive, multifaceted view of the expenditures associated with different approaches to community care. Publicly funded or centralized systems of health care require more information about all the total direct and indirect costs if we are to understand the total cost associated with the care provided, rather than looking only at which department bears the cost. Our work suggests that the failure of either the health system or the social service system to meet its clients' needs will lead clients to seek help from the other system. Similarly, a planned reduction in expenditures in one system may increase costs to the other, particularly if access is restricted. What may be counted as a reduction in cost to one system appears as an increase in cost to the other or shows up as a transfer out of the public system into the private sector, either as a private insurance claim or an out-of-pocket expenditure.

We know from prior research (Kemper 1988; Weissert and Cready 1988) that home- or community-based demonstration programs may not always reduce total program costs because decreases in the use of other health care services may not be large enough to offset the costs associated with the provision of a more comprehensive array of home or community services. Expenditure data in our nine studies include home- or community-based program costs. Even when these costs were calculated as part of the total expenditure, that total figure was usually lower when the fuller array of community health and social services was provided programmatically (i.e., proactively and without regard to funding sources).

An exception was found in the case of services for underserved, marginalized (Byrne *et al.* 1995; Voorberg 1995) minority (Majumdar *et al.* 1996) populations with problems of access. In studies of these populations, increased (Byrne *et al.* 1995) or equivalent (Majumdar *et al.* 1996) expenditures meant that access to community services improved, suggesting that the most vulnerable clients are most negatively affected by access reduction. Because they have poorer outcomes and use more services, they are at risk of being even further excluded from services by programs that target the populations likely to have the best outcomes at the lowest per person cost.

When there are conflicts between individual and societal perspectives, often seen as a disparity between client need(s) and public willingness to pay, policy makers have to find ways of compensating or cross-subsidizing the community agencies that bear the brunt of equalizing access or achieving savings for the whole care system. We would argue that the most expensive services are those that are not tailored to patient needs. Community agencies need to maintain the less expensive, more accessible, health-promoting, effective approaches to care. Real cost savings arise not from sector-by-sector savings but, rather, from providing client-oriented, comprehensive services. The most expensive services are those that do not match client needs.

In reviewing the studies reported here, we have discovered that our work takes a more comprehensive approach to the system of care and, therefore, to costs. We have included costs to both the health and social systems and to individuals. This broad approach to defining health care and health care costs, across sectors and funding sources, is not found in U.S. literature. Even had we wanted to compare only the health care component of our studies with the health care component of other

(largely U.S.) literature, we would have been stymied by the lack of detail in that literature on the exact cost of each research study measure. As a result, it is impossible at this time to say whether the differences between the two countries are due to differences in systems of care, in the cost items included or excluded in each study, or in the way unit costs were calculated.

However, we believe that the existence of studies demonstrating the potential for savings in one jurisdiction is important for other audiences that are asking what type of system they want and seeking ways to construct it most efficiently. For example, the lesson offered by our studies to jurisdictions that are now providing comprehensive care and wish to expand their current system is that their goals can be achieved more effectively and less expensively than they might have once thought.

A comprehensive approach to creating interagency alliances and joint ventures in service provision has the advantage of preserving agency autonomy and diversity while still providing the relevant health, social, housing, justice, and education services that collectively determine health (Renaud 1997). We also appreciate that without a new policy vision, which requires cooperation supported by funding that depends upon intersectoral collaboration, the programs will not develop. In an environment of competition for scarce resources, it is even more likely that each agency or service sector will channel its energy not into collaboration, but rather into restricting services, reducing demand, and limiting access. In the course of these reductions, more clients will be disqualified from individual service programs and will be less and less likely to benefit from the remaining services. Clients with chronic problems will probably be bounced or shuttled between services that are not designed to provide comprehensive care tailored to their needs. In such circumstances, the personal costs, in terms not just of dollars, but also of time and emotions, will be unnecessarily high.

It has been long recognized that the socially disadvantaged come to health care sicker and in need of more expensive services (Beck 1973; Birch and Eyles 1992; Blaxter 1976; Manga 1987; Edginton 1994; Smaje and LeGrand 1997). In response, we would now argue for preventive health intervention. These studies offer a different perspective because they suggest that health services alone are inadequate to prevent the delay in seeking health care and, hence, the increase in severity and costs associated with medical care of the poor and otherwise socially disadvantaged. This suggests that, for these groups, a proactive approach is

required (Browne, Roberts, Watt, et al. 1994; Weir et al. 1992; Roberts et al. 1995).

There is a real danger, in the light of these findings, that policy makers will extend the reach of the health sector into the social welfare arena and will turn to models of health care and service funding that are inappropriate for the delivery of such services. Already, counseling services in Ontario, even those in the Health Service Organization, are modeled on the fee-for-service, symptom management model of medical practice. Payment to nonphysician providers is based on patient contact hours, and the work related to linking resources, acting as advocates, and establishing interprofessional liaisons is being ignored (Evans 1984). Rethinking models of social care that include these other roles is critical to the achievement of the goals we have set for health.

The main lesson we have learned is that it can be as, or more, effective to offer proactive, comprehensive community care services to chronically ill people with synergistic health and social risks in the early stages of their illness than to provide services piecemeal and on demand. Further, we demonstrated that such an approach is cost effective. The studies of self-selection illustrate that people will try to get what they need to maintain their well-being, and that the type of service and its timing can have either a positive or a detrimental impact on expenditures. The studies that used random allocation illustrate that it may be more expensive in the long run, at least in systems of national health insurance, to ignore people with multiple and interrelated risks. The assumption that more comprehensive, co-coordinated, intersectoral services that foster resilience can create dependency in the form of increased utilization is refuted by the data from these studies.

One final consideration comes from our previously noted "drift" to more expensive health services. It is reasonable to ask if we would have found the same results in another jurisdiction that did not provide universal health services. Because it appears that people seek help as long as their needs are not met, it is likely that a similar drift would occur toward any insured or otherwise affordable service.

Further exploration is required, not only of the costs of care but also of who bears them. For example, we know that copayment within insurance systems does not decrease the overall use of services but rather delays or restricts access only for the group that cannot afford the copayment (Barer, Bhatia, Stoddart, et al. 1994). Selby, Fireman, and Swain (1996) found a reduction in emergency-room use with the introduction

of a copayment for HMO members. Similarly, Magid, Koespell, Every, et al. (1997) found no delay in seeking care among people with symptoms of myocardial infarction in a private insurance system when a small copayment was added. It may be that when alternative care is possible (i.e., with HMOs) or the situation is perceived to be a matter of life and death, copayment may be used to alter patterns of care seeking. "Excess" availability is consumed by those who can afford to pay; overall costs are not reduced (Evans, Barer, and Marmor 1994). Therefore, we would expect that the "drift" in a private insurance system would be within the bands of public or private services rather than across bands. Only when out-of-pocket expenses exceed available resources, and when an alternative and acceptable source of care is not available within a private service system, would individuals seek assistance in the public sector. We suggest that price becomes a factor of where, rather than if, people seek help. The work of Selby et al. (1996) and Magid et al. (1997) confirms shifts within HMO services (ER to urgent care) with time delays in emergency situations when copayments are introduced. In both studies, however, patients were privately insured, which suggests that they represented at least a modestly affluent portion of the population, for whom it has not been demonstrated that a "modest copayment" is a deterrent to seeking emergency medical care. The evidence on how patients with chronic conditions are affected by the imposition of copayments, in terms of utilization patterns and costs, supports our findings about the effect of reduction in service on the neediest patients.

Selby et al. (1996) also looked at emergency-room care in the context of an HMO, albeit one whose membership covered a wider economic span. They point out the availability of alternative sources of care, including urgent care, which could absorb patients who rejected copayment for emergency care. These arguments may be interpreted as supporting our contention that overall utilization is not decreased but rather is shifted to other, less expensive, sources in circumstances where the patient perceives the user charge to be excessive and the risk of shifting the source of care to be tolerably low. In our studies of integrated care, we demonstrated that this shift can be effected from more expensive to less expensive arms of the health care system and from the health care system to the less expensive social service system. Costs were reduced without compromising—indeed, sometimes even enhancing—the outcome(s). Where people seek help is a major factor in the cost of care.

Conclusions

Although we have reported consistent and, we believe, instructive trends in the studies we examined, we caution that we covered only nine studies and that all were conducted in a common policy environment. It appears that models of institutional health care utilization are inadequate to explain community health service utilization, perhaps much in the same way that acute care models fail to deal effectively with chronic conditions. We need to develop a more sophisticated understanding of how utilization works in the community in order to provide effective and efficient care to people with chronic conditions (Gainer and Watanabe 1997).

Our understanding can only be enhanced by combining the results of quantitative and qualitative analysis. These nine studies mark the beginning of a critical mass. As our bank of studies increases, we anticipate that the emerging themes we have described will be further refined or altered, but this possibility only will only be realized if the full body of data from all the studies meeting the population and location variables we have set forth is treated as a composite source of information.

In the current context of constraint, further trials of health services restructuring should be conducted in the future. Such trials should be designed so as to enable us to analyze client capacities, such as coping skills and perceptions about purpose in life, as they interact with various treatment approaches. This type of information can be used to justify priorities for service mix and to ensure that certain high-risk subgroups receive enhanced services.

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Address correspondence to: Professor Susan Watt, DSW, System-Linked Research Unit on Health and Social Service Utilization, McMaster University, Faculty of Health Sciences, Room 3N46, 1200 Main Street West, Hamilton, Ontario, Canada, L8N 3Z5.