ABSTRACT

The goals of the study were to describe the clients of home care and their care providers; to determine the competencies required to provide their care; to determine the costs of the formal care providers per client diagnoses; and to determine the burden of care for a randomly selected sample of informal care providers. Forty-nine percent of the 773 clients who participated in the study were age 70 and older and 63% were female. Forty-one percent of clients lived with a spouse but 24% lived alone. The most frequent primary diagnoses (reason for admission to program) were arthritis, stroke, fractures and sepsis. Discipline experts determined the competencies required to provide the care. Variations in costs across the same diagnosis were related to the category of providers assigned and to the frequency of provision of care strategies. The constant dependency of the client was perceived as the greatest stressor for informal providers.

ABRÉGÉ

Les objectifs de l'étude comprenaient : l'établissement du profil des clients des soins à domicile, la détermination des compétences nécessaires à la prestation des soins, l'évaluation des coûts des interventions et du fardeau sur les soignants du milieu. Quarante-neuf pour cent des 773 clients étaient âgés de 70 ans et plus et 63 % étaient des femmes. Quarante et un pour cent vivaient avec conjoint, alors que 24 % vivaient seuls. Les plus courants diagnostics primaires, motivant l'admission au programme, sont l'arthrite, les accidents cérébraux vasculaires, les fractures et la septicité. Les compétences nécessaires à la mise en oeuvre de stratégie de soins ont été déterminées par des spécialistes dans leur domaine. Les variations des coûts pour un même diagnostic est en fonction de la fréquence des soins et de la catégorie des fournisseurs. La dépendance constante du client était perçue comme le facteur de stress le plus important chez les soignants du milieu.

Home Care Clients, Providers and Costs

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An increase in the elderly population and health system reforms have increased the demand for publicly funded home care services. The range of care strategies provided in the home and the number of different care providers have necessitated the collection and analysis of data on clients and their formal and informal care providers in order to guide policy and planning decisions.

LITERATURE REVIEW

Home care is the assessment, coordination and provision of services to individuals and families in a home setting to improve their health and well-being.¹ Services have been described under three models: maintenance and preventive (assists individuals to live independently and as much as possible prevent further deterioration of their health status); long-term substitution (enables individuals to live at home rather than in an institutional setting); and acute care substitution (provides services in the home that would otherwise be provided in an acute care facility).² A comprehensive literature review to determine the cost-effectiveness of these models concludes that the quality of existing research is limited and that there is a scarcity of Canadian studies.³ The largest portion of home care clients are elderly females, and nearly a third of them live alone.⁴ As the level of dependency of the

client increases, the level of burden on the informal caregiver (family, friends) also rises.⁵ Policy makers and service providers must consider the long-term consequences resulting from delays or disruptions in life course development because of caregiving responsibilities (e.g., putting aside plans for education, childbearing),⁶ and the financial burdens imposed on both clients and informal caregivers.⁷

Shorter hospital stays and more treatment in the home to avoid hospitalization, have contributed to the complexity of care provided in the home. Consistency of care provider, standards, clinical guidelines and care mapping have been promoted in order to maximize the effects of care strategies, to contain costs and to track goal attainment.^{8,9} A description of the competencies (knowledge, skill and clinical judgement) required to provide the care would assist educators, recruiters and planners. Standards relating to recruitment, training and role are particularly needed for unregulated home care workers.¹⁰

Both for-profit and not-for-profit agencies provide home care services, and labour is the largest single expense category of most home care businesses.¹¹ All Canadian provinces have publicly funded home care programs but several provinces contract for home care services through a request for proposal process. Therefore, the establishment of reimbursement scales and competency standards for formal care providers would ensure that the element for competition is quality of care rather than the price of services.¹¹ A provincial and a national data base describing the client population, the care strategies, and the competencies required to provide the required care is lacking but essential to home care policy development and planning.

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STUDY GOALS

The goals of the study were to: 1) develop a profile of clients in one Ontario Home Care program; 2) identify the care strategies and competencies required to provide care; 3) provide a profile of the service agencies; 4) identify the categories of formal providers assigned to provide the strategies; 5) provide the cost of formal care providers for newly admitted clients over a four-week period; and 6) provide a measure of the burden of care experienced by informal care providers.

METHODS

Clients admitted to the Home Care Program in October 1996 were invited to participate in the study. Information about clients, care strategies and categories of providers was obtained from Home Care Program documents. The Burden Interview Tool¹²⁻¹⁴ was administered to a stratified random sample of 24 informal providers. Total and subscale scores were calculated and information freely offered by informal providers was analyzed along the thematic lines of role strain, financial stressors and social limitations. Discipline experts analyzed the care strategies provided by their discipline to determine the competencies required.

Information about agencies and their personnel and services was obtained through a structured interview with each agency director. Cost estimates of the formal care providers were calculated (fee times frequency of service) per primary diagnosis; per primary diagnostic group; and across the total number of diagnoses (primary and secondary) for a four-week period.

RESULTS

Client profiles

Of the 773 clients who consented to participate in the study, 49% (381) were age 70 and older and 63% (486) were female. Only 6% of the clients were less than 15 years of age. Forty-five percent (345) were ages 15-69. Although 25 different maternal languages were identified, 82% of clients spoke English and 12%

spoke French. Almost one half (48%) had received home care at some time previously. Fifty-one percent of clients required acute care with 40% requiring medical/surgical care. Forty-seven percent were long-term-care clients with the predominant subcategories of rehabilitation and functional support. The remaining clients (2%) were school health clients. Ninety-two percent were urban dwellers and 8% rural.

Referrals of clients came primarily (537, 70%) from hospital physicians, followed by community-based physicians (158, 20%); community nurses (29, 4%); community sources such as friends, day treatment programs (19, 3%); non-physician/nurse hospital personnel (11, 1.4%); hospital nurses (3, 0.4%); self-referrals (3, 0.4%) and other health professionals in the community (2, 0.3%). There were missing data regarding the referral source for 11 clients. Living arrangement information was available for 766 clients (see Figure 1).

Although diagnoses were missing for some clients, 161 primary diagnoses (reason for admission to home care) were identified. Across all age groups, the four most frequent diagnoses were arthritis/osteoarthritis, stroke, fractures and sepsis. The most frequent diagnoses in the 70+ age group (n=378) were arthritis/osteoarthritis, stroke, fractures, and con-

gestive heart failure; and in the age group 15-69 years (n=342): sepsis, arthritis/osteoarthritis, breast cancer and loss of skin integrity. Clients under the age of 15 (39) presented with a diversity of diagnoses, the most common of which were: newborn monitoring and feeding issues; developmental delay, speech disorder, and fine and gross motor difficulty. Eighty-one percent of all clients had one or more secondary diagnoses and 44% had two or more secondary diagnoses. The most frequent secondary diagnoses were hypertension, diabetes and arthritis/osteoarthritis.

All medical diagnoses were grouped during the analysis phase (e.g., diabetes into endocrine). When the primary and secondary diagnostic groups were combined for 759 clients, 54% (408) had a diagnosis relating to heart, vessel and blood diseases/disorders; 54% (406) also had a bone-related disease/disorder and 23% (175) had some form of cancer.

The top four treatment goals were: teach treatment protocol (24%), assist adjustment to altered functional status (20%), heal wound (14%), and return to self care (14%).

Prescribed care strategies

There were 128 different care strategies (interventions) prescribed, and 38 were provided by more than one category of for-

TABLE I
Highest Formal Provider Costs per Primary Diagnosis

Primary Diagnosis	Total Cost	Mean Cost	Minimum Cost	Maximum Cost	N
Sepsis	27,192.30	824.0	75.50	1734.90	33
Osteoarthritis/Arthritis	26,183.90	385.1	61.00	1325.70	68
Stroke	20,031.50	527.1	37.80	1697.40	38
Loss of Skin Integrity	19,012.00	731.2	113.30	1963.00	26
Fractures	17,574.80	502.1	61.00	2029.40	35
Congestive Heart Failure	15,009.80	577.3	122.00	1476.00	26
Breast Cancer	14,616.70	584.7	75.50	1785.40	25
Lung Cancer	13,369.10	835.6	151.00	2192.80	16

mal care provider. Sixteen clients had more than one category of provider enter the home to provide the same care strategy. By examining the competency charts developed by the discipline experts, it could be determined that the assessment and interventions employed differed across the categories of providers who were assigned the same or similar care strategies. This is an important observation in view of discussions about the introduction of "generic" professionals. For example, pain management was assigned to the registered nurse or physiotherapist. The registered nurse employs cognitive dissociation techniques, guided imagery, relaxation techniques, administration of analgesics, provision of information and emotional support. The physiotherapist uses transcutaneous electric nerve stimulation, ultrasound, laser, exercise, massage, and the application of heat or cold. Both disciplines provide pain management but the provider chosen depends on the competencies required for the specific client.

The care strategies most frequently provided by home support workers were not personal care strategies as expected but bathroom cleaning (31% of clients), making beds or changing linen (31%) and vacuuming (30%).

Service agencies and formal care providers

Home care services were provided by 10 for-profit agencies and 6 not-for-profit agencies which includes the Home Care program as the employer of the case managers, social workers and the majority of occupational therapists and physiotherapists. Consistency of care provider is a major issue for clients and some agencies were able to offer consistent provider/client assignments 100% of the time, whereas other agencies had difficulty in meeting the

75% consistency standard set by the Home Care Program. There was also variability across agencies in their ability to match clients and providers for language. Policy and procedure manuals were used by 80% of the agencies. Orientation for new staff ranged from 3 hours to 5 days depending on the agency.

The Agency Directors agreed on the need for education standards, practice regulations and the consolidation of current levels of unregulated workers into one or two categories of personal support workers. There was also support for ongoing third party review of home care services through a participatory process which includes the agencies to ensure quality care.

All clients were assigned a case manager to ensure comprehensive, coordinated service delivery and to serve as the key contact with the client and family. The formal care providers included nurses, physiotherapists, occupational therapists, nutritionists, social workers, speech pathologists and home support workers. The majority of home support workers and several professionals work on contract as casual staff.

Cost of care

Table I identifies the primary diagnoses with the highest formal provider costs during the one-month study period.

The minimum and maximum costs per diagnosis demonstrate the variability of the amount of care required from formal care providers for clients with the same primary diagnoses.

The greatest standard deviation in costs for primary diagnostic groups was across clients with diseases/disorders of the kidney and urinary tract and the lowest standard deviation was for clients within the mental health, endocrine and reproductive system groupings.

Arthritis/osteoarthritis was the most common primary diagnosis with the total costs for 68 clients being \$26,183.90. Sepsis (wounds, post-surgical infections, abscesses and empyema) generated the highest total cost over one month: \$27,192.30 for 33 clients.

An analysis of costs across clients with the same primary diagnosis offers a rationale for the variation in costs across the same diagnosis. For example, a client with schizo-affective disorder received 4 visits from a registered nurse and 18 hours of service from a home support worker for a cost of \$441.54; another client with the same diagnosis received 4 visits from an occupational therapist and 16 hours of service from a home support worker for a cost of \$597.76. The difference in cost relates to the difference in fees across disciplines. The variation in cost also relates to the client's health status and the client's and family's characteristics. A comparison of services delivered to two clients with congestive heart failure revealed that one client received 4 visits from a nurse, 14 hours of service from a home support worker, 1 visit from a nutritionist, 3 visits from an occupational therapist and 4 visits from a physiotherapist for a total cost of \$931.57. The other client received 28 nursing visits for a total cost of \$1,057.00. The case managers identified the coping ability of the client and the family as well as the family's wishes as core reasons for variations in service levels.

Burden of care for informal providers

A stratified random sample of 24 informal providers (12 with acute care and 12 with long term care relatives or friends) included a foster mother (1), sister (2), female spouse (10), mother (1), daughter (5), female friend (1), male spouse (2) and son (2). In one situation, a son and daughter were co-informal providers.

Informal providers were asked, "Overall, how burdened do you feel?" Fifteen percent said extremely, 5% quite a bit, 25% moderately, 30% a little and 25% not at all. The items on the Burden tool which recorded the highest indication of burden (responses of nearly always or quite frequently) were: dependence of the relative/friend (63%), expectation of care

from the relative/friend (46%), own health has suffered (29%), have lost control of their lives (29%), don't have enough money (25%), and unable to continue to provide care much longer (25%).

The informal providers freely offered examples of financial stressors, role strain and social limitations associated with home care and caregiving. Financial expenses included the cost of supplies and medications as well as the depletion of life savings to cover the cost of renovations and equipment. Role strain was manifested by difficulty in balancing numerous responsibilities inside and outside the home and situations of role reversal. Social limitations included infrequent visitors, being too tired to entertain and an inability to get away because of the constant dependency of the relative. Most individuals interviewed spoke of both physical and emotional exhaustion, their need to receive education about care strategies and community resources, as well as the importance of continuity of care providers.

DISCUSSION

Questions have been raised about the changes required to allow home care services to provide integrated and substitutable inpatient hospital care and about the performance measures that are required to evaluate the cost-effectiveness and patient outcomes related to home care.¹⁵ Home Care programs already provide care strategies similar to those supplied in hospital for sub-acute care clients with complex care needs. Outcome measures are not yet fully developed and tested and the debate about the cost effectiveness of home care continues. The costing of care provider activity per diagnoses demonstrated variations in care strategies prescribed and formal providers assigned to clients with the same diagnosis, and raises questions about the usefulness of costing per medical diagnoses. The level of informal caregiving available, client characteristics such as secondary diagnoses, stress level, and ability to learn self care, plus the assessment and decisions of the case managers contribute to the variations in care provided and therefore the cost.

For educators and recruiters of home care providers, this study begins to lay a foundation in terms of the competencies required to provide home care. This work should continue both within and across disciplines as well as across provinces so that national standards for home care and appropriate educational curricula can be developed; and managers can be assisted to match providers to client needs. Regularly provided, but often not prescribed or documented are: identification of at-risk clients, client and informal care provider teaching, and emotional support. Some terminology describing the prescribed strategies requires clarification. For example the medication monitoring provided by a home support worker refers to observation of the client taking the prescribed medication, whereas the medication monitoring of the RN relates to clients with complex health needs who are prescribed several medications with the potential for drug-drug interactions and severe side effects. This requires knowledge of drug-drug and drug-client condition interactions as well as strong assessment skills.

Information obtained from the small sample of informal providers interviewed calls for research on the financial costs to clients and informal providers of care at home. The constant dependency of the relative/friend and the exhaustion and conflicts related to the responsibility of providing various care strategies indicates that more attention must be given to the needs of informal providers.

The client profiles help to establish priorities for health promotion, illness and accident prevention and for further research. The ongoing research into the prevention of falls in the elderly is particularly important considering the frequency of bone-related conditions, ischemic conditions and fractures in the elderly, as well as the fact that 24% of clients live alone.

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