Independence among Older Adults with Disabilities
The Role of Formal Care Services, Informal Caregiving and Self-Care

FINAL REPORT

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EXECUTIVE SUMMARY

The focus of this program of applied research was on how self, informal and formal community-based care come together to support the independence and autonomy of older persons attempting to cope with chronic illness and disabilities in the community setting. Its specific objectives were: (1) to examine how self, informal and formal care in the community come together, forming patterns of care, among older adults with chronic illness and disability; (2) to address the relationships between these patterns of care and the personal, social and health characteristics of individuals; (3) to assess relationships between these patterns of community-based care and medical (physician) and institutional (hospital, nursing home) care; and (4) to examine the implications of various patterns of care for maintaining independence among older adults with chronic illness and disability.

To achieve these objectives, a multi-method approach was used. It combined in-depth qualitative interviews conducted on an one-to-one or group basis with older individuals and others in the community, structured interviews with older adults receiving and not receiving publicly-funded home support services as well as secondary data documenting the utilization of physician, hospital, nursing home and home care services. The research was conducted in the Capital Regional District (CRD) of Vancouver Island, British Columbia between November, 1994 and March, 1998.

The findings revealed that self, informal and formal resources all tend to be widely used in the provision of care. While self-care was the single most prevalent source of care, the most common patterns of care involved task sharing among self, informal and formal sources. Both complementary and supplementary relationships were evident between the different sources of care. There was no evidence to indicate that those receiving greater formal care also received less extensive informal care or engaged in less extensive self-care (i.e., the substitution of formal for other sources of care). Instead, each was found to increase in conjunction with health needs and access to social and economic resources. As well, no direct relationships were found between levels of self-, informal and formal care and the utilization of physician and hospital services. Nor were they related to older adults’ perceptions of independence. Instead, perceptions of independence were directly and more strongly related to health status, economic and social
resources. Those with better health and better access to economic and social resources considered themselves the most independent.

These findings have important implications for theory and research in the areas of aging, health and health care. They also have applied relevance for policy and practice. In particular, they suggest a need for policy and service delivery decisions not to be based on the assumption that older adults with higher levels of chronic illness and disability do not engage in self-care or are unable or unwilling to do so. The use of alternative therapies also needs to be acknowledged. Also, while attention should be directed towards the horizontal integration and coordination of self-, informal and formal care, there appears little need for concern that increases in the availability of formal services will be associated with decreases in levels of self-care or informal care. However, there is a need for equity issues to be considered in relation to access to home care as well as other health services. Finally, our findings suggest that assessments of dependence and independence should not be made on the basis of the receipt or non-receipt of care. Rather than care, health status, economic and social resources can be used to assess risk for losses to independence.
1. INTRODUCTION

This final report documents the procedures used and synthesizes the results obtained from a three-year Seniors Independence Research Program (SIRP) of Applied Research entitled "Independence among Older Adults with Disabilities: The Role of Formal Care Services, Informal Caregivers and Self Care" (#6610-2121-602). The research program began formally in November, 1994 and ended in March, 1998. Its main focus was on patterns of care involving self, informal and formal care and their implications for independence and autonomy among older persons coping with chronic illness and disability in the community setting. The research was conducted by a research team that included Margaret Penning, PhD, Centre on Aging and Department of Sociology; Neena Chappell, PhD, Centre on Aging and Department of Sociology; Peter Stephenson, PhD, Department of Anthropology; Holly Tuokko, PhD, Centre on Aging and Department of Psychology; and Lorne Rosenblood, PhD, Professor Emeritus, Department of Psychology, all from the University of Victoria. It was carried out in conjunction with partners representing interested stakeholder groups - seniors, informal caregivers, service providers, and regional and provincial health authorities.

This report is divided into four sections. The first section outlines the four major research objectives included within the overall program of research. The research methods used to achieve these objectives are then described. This is followed by a discussion of the key research findings obtained from the various component studies and by a discussion of the theoretical, policy and program implications of the research findings. The conclusion outlines directions for future research.

2. RESEARCH OBJECTIVES

It has been estimated that by the time the baby boom generation reaches old age, 25% of the Canadian population will be 65 years of age and older. Given that physical health declines as people age, there is concern among policy makers and others that the increasing proportion of seniors will place growing demands on health care services which can't be met. This is particularly so since the number of those in the oldest age group - those aged 85 and over - who
are the greatest risk of health problems are growing at an even faster rate. These concerns about the aging of the Canadian population together with escalating health care costs and demands that services be improved to better correspond with consumers’ needs have served as catalysts for health reform. Current trends in health reform include shifts from institutional care to community care, from medical care to health and social care, and from provider-driven to consumer-driven health services. As a result, one finds increasing emphasis being placed on needs to enhance self-reliance, increase access to the informal care available within family and friendship networks and strengthen community-based services as the cornerstones of an alternative and more integrated health care system. It has been argued that, in addition to halting the rise in health care costs, such a modified health care system will be more appropriate for meeting the needs of an aging population and will better maintain the independence, autonomy and dignity of seniors than the currently medically-driven, institutionally-based system (Barer, et al., 1986; Chappell, 1993; Estes and Wood, 1986; Mhatre and Deber, 1992).

To date, extensive research has been conducted focusing on informal caregiving and the use of formal services (primarily the use of physician and hospital services but also, community-based services) considered individually. It has been well-documented, for example, that older adults want to remain living in the community and in familiar surroundings as long as possible (McAllister and Hollander, 1993; Wigdor and Plouffe, 1992) and that informal caregivers are the mainstays of support to seniors, providing between 75% and 85% of all the care received (Kane, 1990). It has also been shown that from 10% to 15% of seniors in general (Chappell, 1989; Doty, 1986) and from 25% to 35% of seniors with higher levels of illness and disability in particular (Soldo et al., 1989) receive care at any one time from the community-based long-term care system. Those who use these services tend to be those most in need, due to chronic illness and disability as well as a lack of access to social and other resources (Chappell and Blandford, 1991). Somewhat less is known about self-care; those activities individuals undertake to promote their own health, prevent disease, limit illness and disability, and restore health (Levin and Idler, 1983). Yet, self-care has been said to represent the basic level of care used most of the time by all age groups in all societies (Dean, 1981). It has been estimated, for example, that from 70% to 90% of all illness episodes are treated without recourse to expert knowledge (Blumhagen, 1980).
Despite their importance to health policy and to the health and well-being of older adults, relatively little remains known concerning the relationships that exist between self-, informal and formal systems of care. While some research has addressed the relationships between informal and formal care within the community setting, as yet, little is known about the relationships between self-care and both informal and formal care. No research has examined the relationships between all three different types of care — self-care, informal and formal care — and how these types of care come together, forming different patterns of care. Nor has research examined the factors that influence these patterns of care or the influence of different patterns of care on seniors’ independence and autonomy.

This program of applied research therefore sought to address these issues, focusing on the role of formal community-based services, informal caregivers, and self-care for maintaining independence in later life. Its primary objectives were:

- to examine how self, informal, and formal care come together, forming patterns of care, among older adults with chronic illnesses and disabilities;
- to address the relationships between these patterns of care and the personal, social and health characteristics of individuals;
- to assess the relationships between these patterns of community-based care and the use of medical (physician) and institutional (hospital, and nursing home) care; and finally
- to assess the relationships between different patterns of care and independence among older adults with chronic illness and disabilities.

3. RESEARCH METHODS

The program of research was located in the Capital Regional District (CRD) of Vancouver Island, British Columbia. This was considered an appropriate setting for several reasons. In 1995, almost one-fifth (18.6%) of the region’s population was aged 65 and older. The CRD includes Victoria which, as Canada’s premiere retirement city, currently has some communities in which seniors represent 25% of the overall population. It is estimated that by the year 2031, approximately one-quarter of Canada’s population will be 65 and over (McDaniel, 1986). Thus,
the figure that will apply nationally when the baby boom generation reaches old age is already evident here, providing researchers and policy makers a unique window on Canada’s future.

Health reform was already well under way in the region before the research commenced, with recognition of informal caregivers and seniors themselves within a service delivery model highlighting community rather than institutional or medical care. Since 1991, the CRD has had a policy of not adding any long-term care facility beds to the system and has relied on the expansion of home-based services to meet the needs of the growing population of long-term care clientele. As a result, the population of long-term care facility residents decreased by 7.0% from 1988 to 1993 while the population of home-based care clients increased by 44.5%. This region was also the first in the province to undergo regionalization, with responsibility for health services being transferred from the provincial to regional health authorities (now the Capital Health Region) in April, 1997.

A multi-method approach was adopted in order to address the research objectives. This approach combined in-depth qualitative and focus group interviews, more structured in-person interviews with seniors, as well as existing data on the utilization of physician, hospital, nursing home and home care services. Each component is discussed below:

3.1 Literature Reviews, Focus Groups, Workshops

Beginning in November, 1994, extensive literature reviews (English, French), consultations involving researchers and community partners, several focus groups and a participatory workshop with multiple stakeholder groups were conducted in order to examine the meanings assigned to the concept of independence and to review the measures developed to operationalize it. From the outset, independence was conceptualized as being distinct from either chronic illness or disability on the one hand or the receipt or non-receipt of care on the other. The methods adopted here were considered necessary in order to validate this conceptual approach as well as to identify appropriate measurement tools.
3.2 Qualitative Interviews

Several sets of qualitative interviews were conducted during the course of this research program. In 1995, the literature review, examination of secondary data sources, focus groups and workshops were augmented by a series of in-depth ethnographic interviews conducted on a one-to-one basis with a non-probability sample of 19 seniors aged 67 to 100 years old. The focus of each of these interviews was on older adults’ understanding of the concept of independence and how they expressed that understanding in their own terms. A further 20 interviews were added in 1996 to permit further exploration of the themes identified in the initial set of interviews. Each interview lasted an average of two hours. All interviews were taped and later transcribed and the data analyzed utilizing QSR- Nudist.

In 1997, a second round of in-depth qualitative interviews was conducted to supplement the structured survey data with more detailed probing of issues relevant to self-care, the use of alternative health care practices for the relief of chronic pain, home care service use and independence. Initially, 40 older individuals (10 male and 10 female home support service users as well as 10 male and 10 female non-users) were interviewed. These individuals were selected from the sample who responded to the structured interviews. Again, the interviews were taped, then transcribed, and their content analyzed to identify patterns of discourse.

Two additional sets of qualitative interviews were also conducted in 1997: one with a sample of alternative health practitioners (n=5) and their older clients (n=15) who regularly used chiropractic, herbalist, naturopathic, traditional Chinese medicines and acupuncture and the other with a sample of 14 Chinese elders. These interviews, not part of the original proposal, were conducted in response to issues raised in the earlier interviews. The former interviews addressed two key questions: (1) How effective are alternative therapies perceived to be by both seniors and practitioners when used to treat multiple chronic conditions?; and (2) Does using alternative therapies contribute to an older person’s sense of independence? The latter were designed to explore the role of culture in relation to issues of care and health service utilization.

3.3 Structured In-Person Interviews

Two sets of structured in-person interviews were also conducted over the course of this research program. In 1995-96, following the initial set of qualitative interviews, more structured
interviews were conducted with a sample of 1,012 older individuals with chronic illnesses and disabilities living in the community setting. Fifty percent (n=506) of the respondents were randomly selected from a listing of all those receiving home support services through the regional long-term care program (as of May, 1995). The remainder (n=506, 50%) of the respondents were selected to create a matched (by age, gender, and functional ability) sample of seniors who were not receiving publicly-funded home support services. These individuals were identified using telephone screening interviews conducted with an age-stratified random sample of seniors living in the region. Respondents were asked for descriptive and factual information on background characteristics, health status, sources of informal care and support networks, service utilization and perceptions of independence.

In 1997, all respondents interviewed in the initial set of structured interviews (n=1,012) were recontacted. The purpose of the follow-up interviews was to supplement the descriptive and factual information obtained earlier with more detailed information, particularly in relation to self-care practices, informal and formal care, and independence. During this phase, interviews were completed with 661 respondents including 305 users of publicly-funded home support services and 356 non-users of these services. The refusal rate for this set of interviews was 9%. Others were lost to follow-up because they were deceased, too ill, had been institutionalized or could not be located (28%).

3.4 Provincial Health Care Linkage Data

Following completion of the structured in-person interviews, an attempt was made to link these data sources to one another and to provincial administrative databases (i.e., health services claims data) documenting the respondents’ utilization of physician, hospital, nursing home, and home care services (as well as pharmacare and vital statistics). The Health Claims Data for B.C. are housed at the Centre for Health Services and Policy Research at U.B.C. and are available through application to the B.C. Ministry of Health (Chamberlayne et al., no date). Approximately 70 percent of those who we interviewed provided written permission granting access to these data. Data were requested for the period beginning January 1, 1994. To date, data have been received for January 1, 1994 through March 29, 1996. Data for the remainder of
1996 as well as for 1997 and beyond have also been requested. They will continue to be linked to the individual survey data (and analyses conducted) as they become available.

3.5 Documentary Review

Finally, in order to establish a broader historical and policy context for the research, an examination of changes over time in the allocation of resources to and delivery of home support services within the region and the province as a whole was conducted, using secondary data sources. This was not part of the original proposal. However, the program of research coincided with a period of significant reform and restructuring within both the province and the region studied. This proved to have a significant impact on the research. For example, from January to March of 1995, just as we were about to begin interviewing, a formal review of clients receiving housekeeping services through the regional continuing care program was followed by a reduction of 34.7% in the total number of clients served. In order to target services to those most in need, clients who had been receiving housekeeping services only no longer received services.

Given the importance and potential implications of these and other changes (e.g., restructuring through regionalization as of April, 1997) that were taking place for health care and health service delivery, it was decided to conduct a study examining changes over time in the allocation of health resources and home care services. To address these issues, data on government expenditures and the allocation of home care and other health services (non-nursing services only) were collected for the period from 1988-89 to 1995-96 for both the province and the CRD. These data were drawn from secondary sources including Annual Reports issued by the B.C. Ministry of Health/Ministry Responsible for Seniors and Provincial Public Accounts documents.

4. RESEARCH FINDINGS

Our review of the findings begins with a discussion of findings relevant to each of the four major research objectives pursued within the overall program of research. We then discuss findings derived from component studies included within the overall program of research.
4.1 Patterns of Self, Informal and Formal Care

The first objective of this program of research was to examine the relationships among self, informal and formal care - to determine how these forms of care come together, forming patterns of care, among older adults suffering from chronic illness and disability in the community setting.

Little consensus currently exists at the theoretical level concerning the relationships between these different sources of care. Instead, informal and formal sources of care have been conceptualized in several different ways - as parallel and potentially competing sources of care capable of substituting for as well as supplementing one another and also, as structurally distinctive and therefore, non-replacing but potentially complementary. Those who advance a substitution hypothesis, for example, argue that one type of care tends to be used to replace another. Thus, by providing formal services, it is often asserted that we will tend to replace informal care (i.e., when the latter is unavailable, unable, or unwilling to provide the type or level of care required). In contrast, a ‘task specificity’ model asserts that, because informal and formal groups are structurally unique or distinctive, they are rarely capable either of substituting for or supplementing one another.

To date, findings from research that has addressed relationships between informal and formal care have been limited as well as contradictory. Some studies point to a greater use of formal in-home services (i.e., personal care and home maintenance) among adults with lesser access to informal helpers (Miller and McFall, 1991; Tennstedt, Harrow and Crawford, 1996), suggesting that formal services may substitute for a lack of access to informal care. Others (e.g., Greene, 1983) have reported findings indicating that formal services substitute for informal services even when the latter are available. In contrast, however, others have found no evidence of substitution (e.g., Hanley, Wiener and Harris, 1994). For example, Edelman and Hughes (1990) report findings indicating that formal community-based services generally supplemented rather than substituted for informal care to homebound older adults. Others report positive relationships between informal and formal care, indicating that it is those seniors with better access to informal support resources who also tend to make greater use of formal community services (Logan and Spitze, 1994). There are also findings indicating that social support/informal care is largely irrelevant to formal service utilization, with the use of formal services primarily
determined on the basis of health needs alone (e.g., Moscovice, Davidson and McCaffrey, 1988). As well, a substantial body of literature is available which shows that formal and informal care tend to be complementary (Chappell and Blandford, 1991; Denton, 1997; Tennstedt and McKinlay, 1989).

Noelker and Bass (1989) have argued that there are in fact multiple different patterns of care. Based on their interviews with the primary caregivers of older adults with personal care needs, these investigators found that while the single most prevalent pattern of care within their sample consisted of informal care only (42% of cases), several other patterns of care were also fairly common. In some situations, formal service providers helped with tasks that the informal caregiver did not, while other tasks were shared (i.e., ‘dual specialization together with supplementation’ - 28%). In other situations, ‘dual specialization’ was evident wherein both informal and formal sources of care were involved but provided entirely different types of assistance (21%). The least common pattern of care, within their sample, was ‘supplementation’ - a pattern of care in which formal care providers helped with the same tasks that informal caregivers also helped with. By design, however, their study excluded those for whom formal service providers were the sole sources of help.

According to Chappell and Guse (1989), the most prevalent form of care consists not of formal care in conjunction with informal care but rather, of self-care in conjunction with informal care. To date, however, little explicit attention has been directed to the role of self care vis-a-vis relationships involving informal and formal community-based care. Yet, Dean (1981) has suggested that self-care also interacts in various ways (through substitution, supplementation, complementarity, etc.) with other forms of care.

To examine relationships among self, informal and formal care, we focused our analyses around two questions: (1) What are the various patterns of care that are evident among older adults with relatively high levels of chronic illness and disability living in the community setting?; and (2) What implications, if any, does formal service utilization have for the utilization of self-care and informal care within this group? Data for these analyses were drawn from the structured in-person interviews conducted with home support service users and non-users. Respondents were asked who, if anyone, helped them with various activities of daily living (including personal care activities such as bathing, dressing, and grooming; household management tasks such as light
and heavy housework, meal preparation, shopping; and other activities such as handling day-to-day and long-term finances) as well as what things they did to look after themselves (i.e., devices used, home modifications made, behavioral adaptations employed, etc.).

The findings revealed that self-care rather than informal or formal care was the single most prevalent form of care used for dealing with basic and instrumental activities of daily living - 89% of those interviewed reported engaging in self-care practices, including 93% of those receiving public home support services and 85% of those not receiving these services. However, over three-quarters (77%) of the overall sample also reported receiving formal (i.e., paid) care and 56% reported receiving informal care. Interestingly, over one-half (58%) of those who indicated that they did not receive publicly-funded home support services nevertheless also reported receiving formal care. Variation was also evident across various activities of daily living, with self-care strategies being most widely reported for dealing with personal care tasks such as bathing, dressing and mobility, informal care being most often used for assistance with shopping and formal care being used primarily for help with housekeeping and so on.

Despite the overall prevalence of self-care, the findings also revealed that relatively few people relied on self-care alone (5% overall, 0% of service users, 9% of non-users). Nor did they rely on informal or formal care alone. Instead, the single most common pattern of care involved all three (self, informal and formal) sources of care, with each assuming sole responsibility for providing care in at least one area (thereby indicating task specialization). In addition, however, there were other areas in which two or more of the three sources of care shared the responsibility for care provision. This pattern therefore reflects ‘self, informal and formal care specialization with supplementation’ (21% overall, 34% of users, 9% of non-users). Other fairly common patterns of care for the sample as a whole included ‘self and formal care specialization’ (18% overall, 13% of users, 23% of non-users) and ‘self and formal care specialization with supplementation’ (16% overall, 25% of users, 8% of non-users).

These patterns of care varied somewhat in terms of prevalence between users and non-users of publicly-funded Home Support Services. In particular, those involving supplementation (i.e., self and formal care specialization with supplementation or self, informal and formal care specialization with supplementation) were found to be more characteristic of service users than non-users. Non-users, in contrast, tended to have patterns characterized by specialization only
(i.e., self and formal care specialization; self, informal and formal care specialization, and self and informal care specialization).

To the extent that self, informal, and formal systems of care operate as distinct or parallel and competing sources of care, one would expect findings indicating that greater utilization of formal services will be accompanied by a reduction in people’s reliance upon informal or self care. Therefore, findings that self, informal and formal care seem not to be used to replace or displace one another but rather, to provide assistance that both complements and supplements one another, appear inconsistent with the likelihood of substitution.

Whether enhancing formal services will serve to discourage self-care (thus, self-reliance) as well as informal caregiving by family and friends (i.e., substitution hypotheses) is of primary concern to policy makers. Therefore, to address this issue directly, additional analyses were conducted wherein levels of self and informal care were separately regressed on levels of formal care. Other variables found in preliminary analyses to be significant predictors of either self- or informal care (i.e., education, living arrangements, functional and cognitive impairment) were included as controls. These analyses, unlike those used in many of the previous studies conducted in this area, acknowledged the possibility of reciprocal relationships between levels of self- or informal care and levels of formal care. Because reciprocity violates assumptions underlying the use of standard OLS regression procedures, two-stage least squares regression analyses were performed.

These analyses revealed no support for the view that those receiving greater formal care engage in less extensive self-care or for the related view that they receive less extensive informal care. This was true regardless of whether the formal care received included publicly- or privately-funded services. These findings therefore challenge the popular notion that increasing reliance on formal home support services will be associated with a decreasing reliance on self- or informal sources of care. Instead, they suggest that older adults with relatively high levels of chronic illness and disability do not rely on one and only one source of care for assistance with activities of daily living. Instead, they rely on several different sources of care. These sources of care come together in different ways and provide assistance that is both complementary and supplementary to that provided by other sources of care.
4.2 Patterns of Care: Correlates and Predictors

Objective two of this program of research was to assess relationships between patterns of self, informal and formal care and the personal, social and health characteristics of individuals. Following Pearlin et al.’s (1981) stress process model, the conceptual framework upon which our research was based, each type of care as well as the various patterns of care that were identified in the earlier analyses were regressed (using hierarchical logistic regression analyses) on various background and contextual factors (e.g., age, gender, education, income, living arrangements, informal network size) as well as primary and secondary stressors (i.e., number of chronic illnesses, functional (ADL and IADL) impairments, cognitive functioning and perceived health status).

Our initial findings revealed that those who utilized the highest levels of self-care for dealing with functional limitations were those with the most chronic conditions and highest levels of functional impairment. They were also those with higher levels of cognitive functioning and better access to social resources (i.e., married and living with a spouse, larger informal social networks). Similarly, those who made the greatest use of informal care were also those with greater functional impairment. In addition, however, they were those with lower levels of education and those who were married and living with their spouse. In contrast, greater use of formal in-home care was positively correlated with age, education, income, the receipt of a subsidy for services as well as with higher levels of functional (IADL) impairment.

Turning to the correlates of various ‘patterns of care’, some of the same general trends emerged. For example, those who relied on all three forms of care with supplementation - the single largest category within our sample - tended to be those with higher levels of functional (ADL and IADL) impairment, better access to social resources (i.e., to be married and living with a spouse) and to be in receipt of a subsidy to offset the cost of the formal services (i.e., those receiving publicly-funded services). Those who relied on self and formal care with supplementation also tended to have higher levels of IADL impairment and to be receiving a subsidy toward the cost of formal services. However, unlike those who also received informal care, they also lacked access to specific social resources (i.e., they tended to be unmarried and living alone) but not others (i.e., they tended to have somewhat larger informal social networks) and had somewhat higher levels of education.
Reliance on self and formal care for help in different areas (i.e., without supplementation) was associated with somewhat lower levels of impairment (ADL) and lack of access to social resources (i.e., those in this pattern tended to be not married and to have smaller informal networks) but higher income levels. In contrast, reliance on self and informal care was not related to levels of functional (ADL and IADL) impairment. Instead, those with this pattern of care tended to be living with others, to have lower levels of education and income and to not be receiving a government subsidy for services.

Overall, these findings point to the importance not only of health but of social and economic factors for differentiating patterns of self-, informal and formal in-home care. Among older adults with chronic illnesses and disabilities, reliance on self, informal and formal care all appear to increase as levels of illness and disability increase. As well, however, those relying on patterns of care that involve formal services tend to have somewhat higher levels of health-related need. Access to informal resources facilitates patterns involving informal care provision while economic resources (personal income and the receipt of financial assistance) facilitate patterns involving formal care and particularly, those characterized by supplementation.

4.3 Patterns of Community-Based Care and Utilization of Medical and Institutional Care

A third objective of this program of research was to examine relationships between patterns of community-based care and the use of medical (physician) and institutional (hospital, nursing home) care.

When interviewed in 1996-97, the vast majority (92.8%) of those in our sample reported having made one or more visits to a physician during the six months preceding the interview. Among those making such visits, the average number of visits reported was 5.1 - almost one per month. The correlations between the number of visits made to physicians and the levels of self, informal and formal in-home care were all positive and statistically significant (i.e., \( r = .085; p < .05 \) with informal care; \( r = .105; p < .01 \) with self-care; and \( r = .128, p < .01 \) with formal care), suggesting that those making greater use of self, informal or formal in-home care also make greater use of physician services.

However, when the number of physician visits reported was regressed on background and contextual factors, primary and secondary stressors, as well as levels of self, informal and formal
care, relatively few predictors emerged as significant. Those that did included gender, perceived health and the total number of chronic conditions. Older men, those who perceived their health status as being poorer and those reporting more chronic health problems also tended to report more visits to physicians. Although OLS regression analyses also revealed findings indicating that, with these factors controlled for, those receiving more extensive formal in-home care also made more visits to physicians while those receiving publicly-subsidized services made fewer visits, these relationships were not confirmed within the two-stage least squares analyses. Thus, these relationships appear attributable to bias introduced into the equation as a result of the reciprocal relationships (i.e., two-way causation) evident between formal community-based care (both privately- and publicly-funded) and physician care.

Turning to hospital service utilization, about one-third (33.4%) of those in our sample had been hospitalized for one or more days in 1995. The average was 12.4 days. Just over eleven percent (11.3%) had been hospitalized during the first three months of 1996 (mean = 7.9 days). A comparison of the average levels of self, informal and formal in-home care evident among those who had and who had not been hospitalized during each of the two periods revealed no significant differences in levels of self- or informal care. For both periods, however, average levels of formal care were found to be significantly higher among those who had been hospitalized than among those who had not. This likely reflects their poorer health. Subsequent multivariate analyses revealed none of the three level of care variables (i.e., self, informal or formal) to be significant predictors of the use of hospital services once differences in health status and other factors were controlled for.

As of 1996, none of those in our sample were confirmed (using the health claims data) as being in long-term residential care. Consequently, analyses of the implications of self-, informal and formal community-based care for the utilization of long-term residential care will be pursued once the health claims data for the remainder of 1996 and 1997 become available. Our analyses of the relationships involving physician and hospital services will also be confirmed once these data become available. To this point, however, our findings suggest that there is likely no direct relationship between levels of self, informal or formal in-home care and the utilization of physician or hospital services.
4.4 Patterns of Care: Implications for Independence

The fourth major objective of this program of research was to assess relationships between different patterns of care and independence among older adults with chronic illnesses and disabilities living in the community setting.

From the outset, our research program conceptualized independence as being distinct from the receipt or non-receipt of care. The view that self-care is more or less synonymous with and reflects independence and that the introduction of informal and then formal sources of assistance reflects increasing dependence underlies the majority of research in the area. It is also widely used in the health policy and service delivery arenas. As noted by one author, “long-term care involves a continuum of programs and services that fit the needs of the elderly population, depending upon their stage of dependency” (Cicirelli, 1992:5).

An alternative conceptualization, and the one used in this program, sees self, informal, and formal care not as benchmarks of dependency but rather, as representing resources that are used by individuals to cope with stressors such as the functional limitations imposed by chronic illness and thereby, maintain or enhance independence. According to this view, one can be independent despite being in receipt of formal services. Indeed, the receipt of formal services may assist one to be independent. Independence, as used here, is therefore considered to be multidimensional and includes both subjective elements having to do with perceptions of autonomy and control over decision-making as well as to more objective (behavioral) elements concerning the ability to engage in desired activities and maintain a personally desired style of life.

Although ‘at-risk’ in terms of health and often receiving care, the vast majority of the older adults surveyed nevertheless felt in control of their lives, independent, able to make their own decisions and to pursue a desired style of life. For example, 89.0% of those interviewed in the first set of structured interviews reported being able to make their own decisions most or all of the time, 83.1% reported that they felt in control of their lives most or all of the time, and 81.6% stated that they felt independent most or all of the time.

Negative correlations were found between several of our measures of independence and mastery and levels of self, informal and formal care, revealing a general tendency for those receiving greater care to report lower levels of perceived independence. Therefore, in order to explore these relationships further, multivariate analyses were conducted wherein each of these
three different measures of independence was regressed on background and contextual factors, primary and secondary stressors and finally, levels of self, informal or formal care. These findings revealed that neither formal, self- or informal care were directly related to perceived levels of independence once other relevant factors (e.g., health status) were taken into account. Also, while levels of self-care and formal care were both negatively correlated with perceptions of mastery at the bivariate level, multivariate analyses revealed positive relationships between self- and informal (but not formal) care and older adults’ perceptions of personal mastery.

Overall, these findings provided little evidence to suggest a direct relationship between levels of care (self, informal or formal) and older respondents’ perceptions of personal independence. Instead, they suggest that their perceptions of independence are directly and positively related to their health and functional status, economic resources and access to social support. Those with higher levels of perceived independence were those with lower levels of functional (ADL and IADL) impairment, better perceived health status, higher levels of income, larger social networks, and those receiving more emotional support. Similarly, those with higher levels of perceived mastery were those who were younger, had lower levels of functional impairment (AADLs), better perceived health and greater emotional support.

These findings suggest that among older adults with chronic illness and disability who are living in the community setting, personal independence is not in fact synonymous with the receipt of care. Nor is it, in general terms, directly related to the receipt of care (self, informal, or formal). Instead, it is most directly and strongly related to health and functional status. It is also related, although in a somewhat less consistent way, to levels of income and social support. These findings therefore confirm the need to differentiate between independence and the receipt of care. However, they also suggest that measures of health, income and social resources can be used to identify those most ‘at risk’ for losses of independence.

4.5 Component Study - Gender and Independence

In 1995-96, prior to the first set of structured interviews, a series of in-depth qualitative interviews was conducted to address people’s understandings of the concept of independence. Two questions were addressed: (1) What does independence mean to someone over 75 who is
considered to be ‘frail’?; and (2) How does one assess the need for support services and then supply these services without compromising this sense of independence?

Analyses of these interviews revealed ‘independence’ to be an important cultural value that was socially constructed and shaped by a number of factors. Gender emerged as one of the most prominent. Moreover, differences were found based upon the genders of both the interviewer and the respondent. Specifically, the findings revealed that older men tended to frame their discussions of independence around such areas as work, careers and the war when they were being interviewed by men whereas older women being interviewed by women tended to focus on independence in relation to family relationships and so on. When the gender of the interviewer was reversed, however, it was found that women respondents being interviewed by men tended to focus on their careers and work lives as well as their families whereas men being interviewed by women now talked about their family lives and relationships as well as their careers. Thus, the data were richer and less gender-specific when the gender of the interviewer and respondent differed.

These findings suggest that discourse concerning ‘independence’ and related issues varies somewhat depending upon social and situational factors such as the gender mix of those involved in the interactions. One potentially important implication of these findings is the possibility that professional assessments of need for services, which are grounded in assessments of independence, may also vary in conjunction with such factors. While further research is needed to determine if this is indeed the case, the importance of considering such issues in the assessment process is clearly indicated.

4.6 Component Study - Home Care, Independence and Medical Pluralism

In 1997, a second set of qualitative interviews was conducted to supplement information obtained from the more structured survey data with regard to issues of self-care, the use of alternative health care regimes, home support services and independence. The findings obtained from these interviews relate to: (a) the use of alternative health regimes for relief of chronic pain; and (b) the use of self-care and home care.

A manifest content analysis of the interview data revealed that while conventional allopathic medicine was the primary mode of medical care utilized by the older adults within our
sample, many nevertheless also employed a broader therapeutic approach that included various alternative forms of health care. Alternative remedies (e.g., vitamin and herbal supplementation, acupuncture, acupressure, reflexology, moxibustion, massage therapy, chiropractic) were said to be most often employed to treat chronic complaints. Among the reasons given for pursuing these alternatives were the ineffectiveness of conventional medical procedures and concerns regarding over- or inappropriate medication. They appeared to be used more often by women and those with higher incomes. Often, however, they were not defined as alternatives but rather, were seen as being ‘dietary supplements’, as ‘common sense’ modes of care, or in fact as ‘conventional’ forms of care (e.g., chiropractic). Respondents noted that they often kept these practices hidden from their physicians although virtually all of those interviewed stated that they liked their physicians and felt they could communicate with them about most other aspects of their conditions.

These interviews also revealed that both those who received home support services and those who did not, utilized many self-care techniques. These were often creative and involved individuals with disabilities in modifying the physical structures of their homes to accommodate their needs (e.g., one person with profound visual difficulties had color-coded her entire home so that she could find things on her own). All individuals thought that their ‘independence’ was augmented or sustained through the provision of services by others; they identified their social support network (which included home care workers) as the most valuable asset. Again, however, those with more wealth appeared to have more access to these resources than did others.

Overall, these findings confirm our previous findings indicating that older adults with chronic illness and disability nevertheless act proactively with regard to their own health. Their use of alternative therapies and self-care techniques can therefore be considered as expressions of their independence.

4.7 Component Study - Alternative Health Practitioners and Older Clients

Interviews conducted with alternative health care practitioners (i.e., herbalist, naturopathic, traditional Chinese Medicine, acupuncture, chiropractic) and their clients once again revealed that clients tended to use both alternative therapies and orthodox Western medicine.
Although alternative therapies were often said to be used in response to dissatisfaction with traditional medical therapies (including frustration with a diagnosis, concerns with prescribed drugs and their side effects, etc.), those clients who were interviewed did not regard alternative therapies as being in opposition to orthodox medicine. Rather, they considered them to be complementary, with alternative therapies considered useful in conjunction with orthodox medical therapies. As with orthodox medical care, few sought out alternative health practitioners for preventative health care.

Among those interviewed, the cost of seeing an alternative practitioner was not considered a disincentive to use. However, in this instance, only users of these services were interviewed. All participants nevertheless felt that alternative therapies should be part of the provincial health plan. This view was shared by the health practitioners.

When asked if alternative therapies contributed to their sense of independence, all participants responded positively, citing enhanced physical functioning, greater responsibility for their health and the perception of choice or control (e.g., over health decisions) as indicators of independence.

4.8 Component Study - Measuring Cognitive Functioning

It is important that cognitive functioning also be taken into account when addressing issues relevant to care and independence in later life. The aging of the population together with health reform initiatives designed to encourage long-term care in the community have meant that an increasing number of people with cognitive impairment are being cared for in the community setting. Yet, before we can begin to effectively address issues associated with the provision of care and maintenance of independence among those with cognitive impairment, there is a need for agreement concerning how to measure and assess cognitive functioning.

Assessments of cognitive functioning often tend to be made on the basis of a variety of measures such as the Mini-Mental Status Examination (MMSE- see Folstein et al., 1975) that include tasks such as the ‘serial sevens task’ which require people to subtract seven starting at 100 and subtracting seven from what is left, five times. For example, this task contributes 5 points to the maximum MMSE score of 30, with a score of 23 or lower generally used to indicate the presence of cognitive impairment (Tombaugh et al., 1996). In a modified version of the
MMSE, the ALFI-MMSE ( Roccaforte et al., 1992), the 'serial sevens task' contributes 5 points to an overall score of 22, with a score of 16 or below used to assess cognitive impairment.

Since poor performance on the serial sevens task alone could result in substantially lowered overall MMSE scores and consequently, in inflated measures of impairment, it was considered important for our study to determine whether or not the ability to calculate serial sevens represents a valid indicator of cognitive functioning. Several previous researchers have presented findings suggesting that this task is, in fact, not appropriate for inclusion based on findings indicating that many of those who are aging normally find this task difficult.

Analyses of data drawn from the structured interviews conducted with users and non-users of home support services revealed that while the number of errors made did not vary as a function of age, approximately one-half of all cognitively intact respondents made at least one error on the serial sevens task. Thus, the task appeared to be a difficult one even for those who did not appear to have cognitive deficits and who were aging normally.

Findings indicating that a relatively high proportion of cognitively intact older adults make errors on this task suggest that it is not useful in discriminating between those with and without significant cognitive impairment. As a result, they also suggest that poor performance on the serial sevens task should not be taken to indicate the onset of significantly 'abnormal' general cognitive decline within the domain of attention and concentration. Thus, it is recommended that the task not be included on screening measures for cognitive impairment used with older persons. While, at present, it is common clinical practice to give persons an option of doing the serial sevens task or spelling the word 'WORLD' backwards, on the basis of these findings, it is recommended that this option no longer be provided and that the serial sevens task no longer be administered for scoring purposes.

4.9 Component Study - Home Care and Health Reform

Health care reform is a central issue on the policy agendas of all levels of government - national, provincial, and regional - both in Canada and elsewhere. The need for a shift of focus and of resources away from acute medical and hospital care and towards community-based services such as home care has been a common theme in documents issued by virtually all Canadian government task forces and royal commission reports over the past 10 years. However,
the extent to which this is actually occurring is not yet clear. Also unclear is whether the shift, to the extent that it is occurring, entails an expansion or redirection of home care services.

To try and address some of these issues in the context of the changes currently under way in the province and the region within which our program of research was carried out, we examined official government data outlining expenditures made on health services and the allocation of home care services for the 8-year period from 1988-89 to 1995-96. The findings revealed that there had been gradual declines in the proportion of the health care budget allocated to medical and hospital services as well as increases in the proportion of the budget allocated to community and other health services including continuing care during this period. However, within continuing care, the proportion of the budget allocated to home care services (i.e., non-nursing services only) had increased somewhat in the earlier years but had then declined in more recent years.

Similar trends were evident with regard to the number of clients served and the number of hours of service provided to home care clients: both had increased from 1989 to 1994 but had then declined during more recent years. In contrast, however, the intensity of the services provided to those receiving services had increased. Although fewer people were receiving services, those who were receiving these services generally received more hours of service than they had in previous years.

The characteristics of the clients served were also found to have changed. For example, during the past few years, the proportion of clients at the lowest levels of care (i.e., personal care) had greatly declined. In contrast, the proportion of clients at the intermediate and extended care levels had increased. As well, the proportions of clients under 65 or over 85 years of age had increased while those of clients aged 65-74 or 75-84 had decreased.

These results, although not definitive, suggest some reduction rather than expansion of community-based home care services during recent years within the province and region studied. They also suggest a trend towards the redirection of these services away from those clients (e.g., those at the lower levels of care and those in the 65-74 and 75-84 year age groups) who tend to require non-medical or supportive services (e.g., help with housekeeping, laundry, etc.) and towards those with more intensive and medically-focused needs (i.e., those at the higher levels of care, those under 65 years of age, and those aged 85 and over). Overall, therefore, they suggest a
medicalization of community-based home care services during the more recent years of health reform.

5. DISCUSSION

This program of research sought to determine how self-, informal and formal community-based care come together to support the independence and autonomy of older persons attempting to cope with chronic illness and disability in the community setting. Four objectives were addressed. Each reflected one of the following questions: (a) First, what is the relationship between self-, informal and formal sources of in-home care - how do they come together, forming patterns of care, among older adults with chronic illness and disability?; (b) How are patterns of self-, informal and formal care related to the personal, social and health characteristics of individuals?; (c) How are patterns of community-based care related to medical (e.g., physician) and institutional (e.g., hospital) care?; and finally (d) What implications do patterns of self-, informal and formal care have for independence among older adults with chronic illness and disability? The findings from this program of research suggest answers to each of these questions.

(a) What is the Relationship Between Self-, Informal and Formal Sources of In-Home Care?

When it comes to issues concerning health care for older chronically-ill adults, researchers and policy makers alike tend to focus their attention more or less exclusively around informal and formal sources of care. It is common to assert, for example, that families are the backbone of the long-term care system and provide virtually all of the care for more highly impaired elderly persons living at home. Our findings clearly support the importance of the informal network. However, they also reveal that self-care, rather than informal or formal care, is the single most prevalent form of care among older adults with disabilities. This is particularly evident when it comes to personal care and household management tasks. However, the importance of self-care is also evident in terms of self-treatment strategies and alternative health care practices. For example, although conventional allopathic medicine is the primary mode of medical care utilized, many older adults also employ a broader therapeutic approach that includes various alternative forms of care. In fact, all three forms of care are widely used - older adults
with higher levels of chronic illness and disability do not tend to rely on only one source of care. Instead, they rely on several different sources including self-care, informal care provided by family members and friends as well as formal services (public and private). These forms of care come together in different ways, creating different patterns of care. The most common patterns involve task sharing with specialized involvement by various sources of care (thus, complementarity among self-, informal and formal care), which may or may not also be supplemented by a sharing of responsibility for other tasks. Also, there is no evidence to indicate that those receiving more extensive formal care (private or public) receive less extensive informal care or that they engage in less extensive self-care. Instead, all appear to increase together, largely in conjunction with increases in needs for care associated with poorer health and functional status.

(b) How Are Patterns of Self-, Informal and Formal Care Related to the Personal, Social and Health Characteristics of Older Adults?

However, levels and patterns of care are not related to health needs alone. Instead, our findings suggest that the use of self-, informal and formal care as well as the patterns of care that result are related to several factors including health-related needs and access to social and economic resources. Those with better access to social resources are more likely to be receiving informal care as well as to be practicing self-care. However, reliance on self- and informal care is also associated with lower levels of education and income. Those with higher incomes are more likely to be receiving formal care as are those in receipt of a subsidy to offset the cost of formal services. However, the patterns of care associated with these two types of economic resources differ. While those with higher income levels tend to rely on self and formal care for help in different areas (i.e., to complement one another), those receiving subsidized services tend to have formal services provide help in different areas as well as supplement the care provided by other sources.

(c) How Are Patterns of Community-Based Care Related to Medical and Institutional Care?

According to our findings, those making greater use of self-, informal and formal in-home care also make greater use of physician services. Those receiving more extensive formal care are
also more likely to have been hospitalized during the period studied. However, this appears to reflect their poorer health and functional status. Once differences in health and other factors are taken into account, no direct relationships are found between levels of self, informal, or formal care and the utilization of physician or hospital services.

(d) What Implications Do Different Patterns of Care for Independence Among Older Adults with Chronic Illness and Disability?

While dependence and independence are often equated with the receipt or non-receipt of care, our findings suggest a clear need to differentiate the concepts. Despite often having poor health and receiving care from others (informal, formal), the vast majority of older adults with disabilities consider themselves to be independent, able to make their own decisions and pursue a personally desired style of life. They are also proactive when it comes to their health and engage in extensive self-care. Their perceptions of independence are only weakly and indirectly related to the receipt of care. In contrast, however, they are directly and strongly related to their health, economic and social resources. Predictably, those with better health and better access to social and economic resources consider themselves to be the most independent.

5.1 Theoretical Relevance and Research Implications

These and other findings from this program of research have relevance for theory and research in the areas of aging, health and health care. They confirm, for example, the need to conceptualize independence as distinct from the receipt of care and to re-conceptualize self-, informal and formal care as resources that may, in certain situations, facilitate the ability to cope with some of the problems associated with chronic illness and disability. They also point to the need to recognize self-care as an important component of the overall system of care and suggest attention be directed towards the relationships that exist between self-, informal and formal care. There does not appear to be a single ‘normative’ pattern of care. Instead, there are multiple patterns that are shaped by such factors as the health needs of the individual and the social, economic, service delivery and health policy contexts within which these needs are situated.
5.2 Policy, Program and Practice Implications

The findings also have implications for health policy, programming and service delivery. Within health planning and health policy arenas, there is an increasing focus on the need to see decision-making guided by evidence-based research. The findings of this program of research can be used to inform policy decisions regarding the delivering of community-based care services. As noted by DeFriese and Woomert (1992:57): “There can be little doubt that the phenomena of self-care and informal care represent a fundamentally important segment of the spectrum of health care services available to meet the health care needs of elderly people... Any rational health policy that does not give full recognition to this... care will provide only a partial view of the national burden of illness and caregiving responsibilities.”

Within health reform, one finds increasing emphasis being placed on needs to enhance self-reliance, including the involvement of individuals with illness and disabilities in the provision of their own care. Our findings which indicate the prevalence of self-care suggest the need for service delivery and policy decisions not to assume that older adults with chronic illness and disabilities do not engage in self-care or that they are unable or unwilling to do so. Instead, it should be recognized that they are already primary providers of their own care.

Findings indicating that older adults with chronic illnesses and disabilities nevertheless rely on several different sources of care, that a number of patterns of care are evident, and that different sources of care tend to come together in ways that both complement and often supplement one another also suggest that each be supported and that attention should be given to the horizontal integration and coordination of formal with other (self, informal) sources of care. This appears to lend some support to the increasingly popular notion of establishing ‘partnerships’ between formal and informal (or self) sources of care. However, the findings also suggest that in pursuing such partnerships, there appears little need for concern that increases in the availability of formal services will be associated with decreases in levels of self- or informal care. Restricting formal services is, therefore, not necessary as a means to enhance levels of self- or informal care. Instead the resources of the formal care system can be made available to support individual clients and their informal carers in their caregiving efforts.

The findings that older adults also often make use of alternative therapies to deal with their chronic illnesses also has important implications. Policy makers as well as physicians and
other health care practitioners need to recognize the role of these alternative forms of health care within our overall health care system. Findings indicating that alternative therapies are often used by those with chronic illness to complement or supplement conventional medical regimens suggest a need to consider their joint role as well. Consequently, physicians and other health care practitioners should not assume non-use of alternative therapies and should consider their implications for conventional therapies.

Evidence indicating that levels and patterns of self, informal and formal care are related to social and economic resources as well as to health-related needs suggests there is also a need for equity issues to be considered in decision-making related to home care services. There also appears to be a need for policy makers to address issues of equity in terms of access to alternative therapies.

Finally, taken together, findings indicating that older adults with chronic illnesses and disabilities are highly proactive when it comes to their own health, that they consider themselves to be independent (able to be actively involved in decision-making and to maintain a desired style of life) and that they do so regardless of levels of care, suggests that assessments of dependence and independence should not be made on the basis of the receipt or non-receipt of care. The finding that older adults’ assessments of independence are directly and strongly associated with better health, social and economic resources lends support for the population health perspective with its focus on the social determinants of health and on improving access to social and economic resources as a means to enhance individual independence and well-being. Rather than care per se, health and functional status, income and social resources can be used to assess risks for loss of independence. Care should be exercised when making assessments of cognitive functioning to exclude the Serial Sevens component of widely-used measures such as the MMSE. As well, findings indicating that seniors and others also discuss independence differently depending upon such factors as gender suggests the need to consider the impact of such issues on decision-making, for example, by those conducting assessments for home care or other services.
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