

**EVALUATION OF THE FIRST LINK PROGRAM IN BC: LOGIC
MODEL (PART I) AND ECONOMIC ANALYSIS BASED ON
AVAILABLE LITERATURE (PART II)**

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PART I: LOGIC MODEL

Issue for evaluation

As it stands now, many people with dementia along with their caregivers either are not informed about the services offered by the Alzheimer Society of B.C. in a timely manner or delay seeking help until they face a crisis or until the burden of caregiving has become too great. This is in part due to the fact that health care professionals do not know enough about the services and supports offered by the Alzheimer Society and how these services might be of value to families. Because of this, the onus is on families affected by dementia to make the connection to the Alzheimer Society.

It is proposed that if the existing services and support programs of the Alzheimer Society aimed at the early stages of the disease were enhanced and better used, there would be less caregiver stress and better health outcomes.

Intervention

The First Link™ program of BC offers:

- a referral service linking patients and their families with the Alzheimer Society earlier in the disease (facilitating access to the Society's programs, information and support services)
- outreach and ongoing proactive follow-up with families to ensure they are linked to the support they need, when and where they need it
- information sessions to improve knowledge of the the First Link program and ASBC programs & services
- networking with health professionals and community service providers to improve dementia service integration

There are also two programs designed for the early stages of the disease - Shaping the Journey: living with dementia™ and Minds in Motion, that are offered alongside First Link and that are funded by a grant from the Ministry of Health Services

Observed results

Observed results of the First Link program to date (in Ontario and Victoria, BC) include:

- earlier linkage of patients and their families with the Alzheimer Society (time between diagnosis and contact has been reduced by 11 months, on average, in pilot implementations of First Link in some Ontario communities)
- participation in and satisfaction with the Sharing the Journey and the Minds in Motion programs
- better knowledge of dementia and community services available for patients and their families
- better knowledge of services available for health professionals and community agencies (creates a service network).

These results are important because they speak to the first hand experiences of individuals with the First Link program.

Caregiver stress and health outcomes

Building on the observed results, the next step is to assess the impact of the First Link program through an economic framework. This requires further observation in terms of:

- caregivers' ability to cope, specifically as it impacts health care service utilization
- costs of the program itself and downstream 'net costs' (after accounting for the changes in health care service utilization patterns- e.g. delayed nursing home placement)

Specifically, in terms of time to institutionalization, a First Link document (Rationale for First Link, June 2010) states that, "the government of B.C. pays between \$160 and \$225

per day for a residential care bed. With First Link, we can possibly trim that cost by at least \$80,000 per person. In the first few years of expansion, by serving 2,000 people annually province-wide, care could reduce costs by approximately \$160,000,000 within a few years of operation”. The economic analysis will seek to validate these estimated savings by improving the downstream service utilization measures and then comparing this impact to the cost of the program. This will provide a clear statement of the value or return on investment for the First Link program with regards to this key expected impact.

PART II: ECONOMIC ANALYSIS

Premise

If the existing services and support programs offered through the Alzheimer Society of British Columbia (ASBC) or other community agencies were better known and used, particularly in the early stages of dementia, it is believed that there would be less caregiver stress and burden, leading to more appropriate use of health care services. The intention with First Link is to achieve earlier referral to the ASBC and, once contact is made, to institute proactive follow-up and linkage to relevant services.

Background

To date, evaluations of First Link both in BC and Ontario suggest that earlier connection to the local Alzheimer Society and earlier use of programs can be achieved and that caregivers and patients can become better informed about the condition and its management. However, to our knowledge, there are no studies that assess the economic value of earlier intervention achieved through a program like First Link in terms of its impact on health care services utilization or on quality of life. There are studies that assess the economic value of drugs in the early stages of dementia and estimate the impact of these drugs on quality of life for that purpose. Other forms of intervention, while often considered desirable, have not been the subject of economic assessment. The purpose of the current analysis is to move the evaluation of First Link forward by providing an economic assessment, on the basis of available information, comparing program costs and benefits.

Impact on Service Utilization

In economic evaluation, program costs are the difference between additional costs incurred and future savings (if any) resulting from the intervention implementation. In the case of First Link, the program is expected to lead to savings in the form of reduced total cost of health care services utilized. The main impact on service utilization is expected to

be on time to institutionalization as it has been demonstrated elsewhere that enhanced support for caregivers can increase the caregivers' ability to cope with the condition and, consequently, delay the need for nursing home placement (1,2).

Relationship between early intervention and service utilization

Nine studies that address the issue of early intervention in Alzheimer's Disease and the impact on service utilization were identified in the literature. However, no studies to date have specifically addressed the impact of *early* support for caregivers. Also, the majority of the studies are from the United States, which limits the generalizability of the results because of the differences in the funding systems (which can directly affect costs and therefore comparability). Nonetheless, the most relevant of these studies is a cost-benefit analysis that found a strong relationship between early diagnosis and intervention in Alzheimer's Disease and net societal savings (3). This study found that programs for early diagnosis and intervention can more than pay for themselves in terms of downstream reduction in service utilization. Our analysis here focuses on delay to institutionalization because most of the available evidence is on linking early diagnosis and intervention to this aspect of service utilization. Should further study of the BC First Link program show net reductions in the utilization of other health care services, the results will be even more pronounced than those presented below.

Economic impact of delay to institutionalization

Noting that any delay to institutionalization will be accompanied by home care related costs during that delay, it is necessary to calculate the net savings resulting from such delays. Further, it is necessary to present out-of-pocket costs and costs borne by the government as distinct categories to assess the extent to which any delay to institutionalization simply shifts costs from government to clients. The first step in the estimation of net savings related to delay to institutionalization is to estimate the costs of institutionalization and of home care. Institutionalization costs used in our analysis are presented in Table 1. The type of room that is occupied (private, semi-private, etc) will impact the overall costs and in order to account for this variation we have attempted to provide average costs based on available information.

Table 1: Residential care costs in British Columbia (per month)

Out of pocket co-payment¹	Health authority cost²	Total cost
Means tested range from \$30-\$98/ day or \$900-\$2940/ month (average of \$1950 per month)	\$135/ day or \$4050 per month	\$6000 per month (taking an average value for out of pocket co-payment)

¹Reference (5); ²Reference (6)

The total cost figure presented in Table 1 is similar to residential care costs reported in the literature from the US (3). It should be noted that government’s reimbursements to nursing homes do not typically vary by stages of the disease.

A more challenging cost to ascertain is that related to home care, and, by extension, if the patient is not in an institution, to relevant adult day care programs. We were unable to find such costs linked directly to the stages of disease in a Canadian context, but a US study suggests mild, moderate and severe Mini Mental State Exam (MMSE)¹ states would incur monthly home care costs of \$924, \$2670 and \$4212, respectively (7). In addition, our search identified a document produced by Manulife Financial that costs out home care and related services for individuals requiring ‘low’, ‘intermediate’ and ‘high’ levels of care, broken down by client out-of-pocket costs and costs borne by the government (8). Across the different levels of care in this report, cost categories included meal delivery/ supervision, personal care, adult day care, medication supervision, laundry/ house cleaning and skilled nursing. Although the scenarios presented in this document have not been explicitly validated against stages of dementia (mild, moderate or severe as measured through the MMSE scores), the descriptions provided as examples of individuals in each of the three levels of services seem to relate to the levels of

¹ MMSE is a commonly used measure of cognitive impairment. Typical states are: normal (score of 25 or more out of 30), mild impairment (21 to 24), moderate (10 to 20) and severe (less than 10).

dementia-related impairment. We thus used the cost estimates from this document for our cost of non-institutionalized care. The detailed cost figures are found in Table 2.

Table 2: Estimated home care and other relevant costs (\$ per month)

Stage of dementia	Client cost	Government cost	Total cost
Mild	937	219	1156
Moderate	1314	529	1843
High	5835	2440	8275

Using the figures presented in Tables 1 and 2, it is possible to calculate the net savings of delays to institutionalization. These figures are presented in Tables 3 and 4.

Table 3: Estimated net savings, per day, of delays to institutionalization, from the government perspective (\$ per day)

MMSE category	Residential care government cost	Home Care government cost	Government net savings per day
Mild	135	7.30	127.70
Moderate	135	17.63	117.37
Severe	135	81.33	53.67

Table 4: Estimated net savings (cost) per day of delay to institutionalization, from the societal perspective (\$ per day)

MMSE category	Residential care total cost	Home Care total cost	Societal net savings per day
Mild	200	38.53	161.47
Moderate	200	61.43	138.57
Severe	200	275.83	(75.83)

Estimate of savings related to First Link’s impact on service utilization

We found that the minimum net savings per day of delayed institutionalization, from the government’s perspective, is approximately \$50 and is over \$120 in mild cases of dementia².

To calculate an estimate for the total expected savings resulting from First Link implementation in terms of delays to institutionalization, three questions must be answered: first, how many more caregivers of people with dementia are expected to receive enhanced support because of the First Link program; second, how are the programs of the Alzheimer Society or of community agencies expected to affect time to institutionalization³; and third, what is the impact of providing these services earlier in the disease progression. We currently have partial answers.

A key source of information with respect to these questions is a long-term, methodologically rigorous, study by Mittelman et al. (1) that found that enhanced support and counseling for caregivers of people with dementia is expected to lead to a median delay to institutionalization of 557 days (about one and a half years). Evaluation surveys of First Link participants in Ontario (9) found many respondents stating that the support

² On average, delays to institutionalization for severe cases of dementia end up costing more from a societal perspective, however one aim of caregiver support is to help in determining the proper care at the right time which addresses those situations where care is not provided in the most efficient way.

³ Note ASBC does not provide counselling for caregivers as part of its programming.

services that they accessed increased their ability to cope with the symptoms of the disease. Improved ability to cope with patient behavior was identified by the Mittelman study as the most important mediator through which the enhanced support services affected time to institutionalization. With regards to the impact of early provision of support services, almost 75% of the participants in the Mittelman study were couples where the care recipient was in the mild or moderate stages of dementia, which is consistent with an intervention that was largely carried out in the early stages of disease progression. Therefore, both the population and the nature of the intervention in the Mittelman study fit the context of First Link. This means that the results of the Mittelman study can be used as a proxy indicator of the size of the expected impact on time to institutionalization *for those cases where there is caregiver uptake of services that would not have taken place without First Link*. Using the results from the Mittelman study in the BC setting, we get an estimated median saving, from the government perspective, of \$29,894.10 for the delay to institutionalization (assuming all institutionalized cases are severe). The per family direct cost of the First Link program can be estimated on the basis of the pilot implementation in Ontario. In Ontario, over the pilot-test period of November 1, 2007 to June 30, 2009, 2,301 clients were referred to the local Alzheimer society through First Link at a total cost of \$640,000. Thus the average cost per referral was \$278⁴. On the basis of the estimated direct costs and expected savings, it can be stated that if 1% of the First Link referrals lead to enhanced uptake of caregiver support services, the program will likely be self-financing (if the distribution of the number of days of delay is relatively normal around the median). If First Link leads to an extra 5% of caregivers accessing early support services, the program can be expected to lead to net savings of approximately four times the direct program costs.

We have no estimate at this time of the impact of First Link on the uptake of available support services by caregivers or of the effect of these specific services on caregiver coping ability. However, a previous evaluation of First Link showed connections with the Alzheimer Society taking place on average eleven months closer to diagnostic date with First Link than without the program (9). Given that families connected with the

⁴ This figure will be updated with data from the Victoria First Link program once it is available; the cost there may be up to \$500 per case, which would take the break-even point to about 2%.

Alzheimer Society are directly exposed to, and therefore likely to be aware of, the services offered by the Society and that these services have been found to improve coping ability⁵, it is suspected that substantially more than 1% of the First Link participants would end up with enhanced caregiver coping ability. This would result in program costs that are zero or negative (i.e. net savings).

Impact on Quality of Life

Our analysis of the impact of First Link on service utilization (specifically, time to institutionalization) suggests that First Link is likely to lead to cost savings. In such cases, the economic evaluation would declare the subject intervention a “dominant” strategy *if* it is not expected to lead to reduced benefits (if it was expected to lead to reduced benefits, the reduction in benefits would have to be compared to the reduction in costs to provide an overall assessment). With dementia, at this time, there is no cure so benefits focus on quality of life.

Calculation of benefits

There is ample evidence to support the notion that early intervention in cases of dementia leads to better quality of life. As Deckosky states, “Diagnosis, treatment and follow-up of Alzheimer’s Disease patients from the earliest stages possible will reduce health care costs and increase quality of life” (10). This notion is echoed by Galluzzi who suggests that there are two main benefits of early identification: first to initiate appropriate interventions early on when patients are most likely to benefit and second for patients and families to have time to formulate a plan as the disease progresses (11).

To estimate the impact of a program like First Link on the quality of life of people with dementia three measurements are required:

- Baseline measures of quality of life

⁵ Survey results of the Ontario pilot project evaluation were inconclusive on this issue but interviews with caregivers found that the Alzheimer Society services and supports improved their ability to cope and manage as the disease progressed (9, p. vii).

- Estimates of quality of life at certain intervals (as the disease progresses) for people with dementia that participated in the program
- Estimates of quality of life at these same intervals for similar patients but who did not participate in the program

The difference in the trajectory of the quality of life measurements between the two groups of people with dementia will provide an estimate of the impact of the program on quality of life.

Measuring improvements in quality of life

A common metric used to measure changes in quality of life is the Quality Adjusted Life Year (or QALY) (12). One QALY equates to one year of perfect health. One year at what would be defined as half of perfect health equates to 0.5 QALY. The QALY is typically used to measure health benefits produced by a given intervention as this measure captures both duration of life and quality of life (12). For example, an intervention that would extend life by one year but causes significant discomfort would be found to produce fewer benefits (fewer QALYs) than another intervention that also extends life by one year, but in perfect health.

Baseline quality of life estimates

A common measure of the level of Alzheimer's Disease or dementia is the Mini Mental State Examination (MMSE). MMSE measures cognitive ability on a scale of 0 to 30 with the higher scores representing lower disease severity. A common classification of dementia severity by level of MMSE is presented in Table 5 (4).

Table 5: Dementia by MMSE categories

MMSE score	Severity of dementia
25 to 30	Minimal
19 to 24.9	Mild
10 to 18.9	Moderate
0 to 9.9	Severe

For people with mild dementia (MMSE scores of 19 to 24.9), there seems to be consensus that the quality of life score is approximately 0.7 - i.e. one year of life equals 0.7 QALYs (13). As might be expected, quality of life is reported to decrease as the severity of dementia increases. Table 6 provides estimates of quality of life for the different categories of dementia, as found in the literature.

Table 6: Quality of life by category of dementia (13)

Severity of dementia	Quality of life estimate
Minimal	0.73
Mild	0.69
Moderate	0.53
Severe	0.38

Progression of dementia

We know that MMSE has been identified as a predictor of quality of life (14). The relationship between MMSE score and quality of life will of course vary by individual but on average, as the MMSE score decreases, so does quality of life. MMSE decline has been estimated at between 1.9 and 3.1 units per year on average (3), depending on whether the individuals are ‘slow progressors’ or ‘fast progressors’ as well as on the effectiveness of drug treatment. Using this information we can model the expected trajectory of quality of life over the progression of dementia from minimal to severe.

Our basic modeling assumptions are as follows:

- MMSE score of 25 at diagnosis
- Annual decline in MMSE score of 1.9 (conservative estimate)
- Dementia progression modeled for 10 years as dementia level plateaus by that point at severe (irrespective of the nature of the early intervention, noting that there is no cure so the main effect of early intervention is a delaying of progression)
- Relationship of MMSE score to quality of life as outlined in Table 6
- Discount rate of 3%

Under these assumptions the expected QALYs over a ten year time horizon are 4.984, meaning that from the initial MMSE score of 25, on average, individuals can expect to experience 4.984 QALYs over the next ten years, or the equivalent of just under 5 years of perfect health over that ten year period.

Impact of First Link on Quality of Life

To estimate the impact on quality of life we also need an estimate of expected QALYs with the program. While there is very little solid evidence on which to base such calculations, a study by Banerjee et al (4) of a program designed to facilitate early identification and intervention in dementia provides some information. For individuals participating in the program, the average MMSE score went from 22.5 at diagnosis to 23.3 six months later (i.e. participants showed no mental deterioration over this period).

Since individuals referred through First Link contact the local Alzheimer society earlier, on average, and are therefore introduced to the society's programs designed for the early stages of dementia earlier, we can expect that a program such as First Link could have an impact similar to that observed by Banerjee et al. We modeled the impact of a 6-month and a 12-month delay in the regression in MMSE scores and calculated the impact on expected QALYs over the same 10-year period as was used in the base case described above. With a 6 month delay, the average expected QALYs were 5.102; with a 12 month delay, the average expected QALYs were 5.278. This means average gains, compared to the base case with no First Link program, of 0.118 QALYs for a 6-month delay and 0.294 for a 12-month delay could be realized.

Conclusion

Our review of the health services literature on early intervention for Alzheimer's Disease has brought us to two main conclusions. First, to date, no formal economic evaluation of First Link, or any similar program, has been conducted. In fact there are very few economic evaluations of non-drug based interventions for dementia as past evaluations tended to be program evaluations, focusing on whether or not the programs met their objectives. In this sense, this work, and even more importantly the prospective study that will follow, provides new information.

The second conclusion is that the First Link program appears very positive in economic terms. On the basis of the available information on the cost of First Link and on the savings related to potential delays to institutionalization, we estimated that if a minimum of 1% of families referred to the Alzheimer Society through First Link end up receiving caregiver services that they would not have otherwise received, the program will likely be self-financed. Any result above 1% will lead to net cost savings. Furthermore, we have established that we do not expect that this cost saving will come at the expense of a reduction in health outcomes. In fact, we estimate that a program such as First Link could lead to an average QALY gain of about 0.12 QALY per First Link referral who receives services that they would not have received otherwise. In terms of cost-effectiveness

analysis, this makes the First Link program a *dominant* strategy, i.e. a strategy that produces similar or better outcomes with less resources and that, therefore, should be funded without the need to consider the opportunity cost (or the value of the best alternative use for the required resources). The planned prospective study, to be initiated in early 2011, will aim at confirming and refining the economic assessment of First Link presented here.

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Appendix – search strategies for literature review

The focus of this study was to determine if there is a link between early intervention and reduction in service utilization. Two sets of search terms were used: 1. Early intervention AND Alzheimer's AND service utilization (and variations of the latter); 2. Intervention and Alzheimer's AND service utilization (and variations of the latter). The variations of service utilization included: health care utilization; health service utilization; utilization; service use; health care service use; health resources/utilization MESH term; health care use. Two databases (PubMed and EMBASE) along with Google Scholar were searched.