UNCOVERING THE COST OF CARE: AN EXAMINATION OF EXTRA BILLING IN BC'S LONG-TERM CARE FACILITIES

by

Judy Harris
BA in Speech Education
Washington State University, 1971

PROJECT SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF PUBLIC POLICY

In the
Faculty
of
Arts

SIMON FRASER UNIVERSITY

Spring 2005

APPROVAL

Name: **Judy Harris**

Degree: **M.P.P**

Title of : **Uncovering The Cost Of Care: An Examination Of Extra Billing In BC's Long- Term Care Facilities**

Examining Committee:

Chair: **Nancy Olewiler**

Nancy Olewiler
Senior Supervisor

Kennedy Stewart
Supervisor

John Richards
Internal Examiner

Date Approved: Thursday, April 7, 2005

SIMON FRASER UNIVERSITY

PARTIAL COPYRIGHT LICENCE

SIMON FRASER UNIVERSITY

Ethics Approval

The author, whose name appears on the title page of this work, has obtained human research ethics approval from the Simon Fraser University Office of Research Ethics for the research described in this work, or has conducted the research as a co-investigator of a project, or member of a course, approved by the Ethics Office.

A copy of the human research ethics approval letter has been filed at the Theses Office of the University Library at the time of submission of this thesis or project.

The original application for ethics approval and letter of approval is filed with the Office of Research Ethics. Inquiries may be directed to that Office.

W. A. C. Bennett Library
Simon Fraser University
Burnaby, BC, Canada

Abstract

This paper examines three aspects of out-of-pocket charges to residents in BC long-term care facilities. Prior studies documenting variability in extra billing and unintended adverse effects from charging patients for medically necessary items and services provided impetus for this research. Caregiver surveys of staff from eight facilities, family expense diaries from four case studies, and a three-year resident billing history from one facility are employed to test methodology for collecting out-of-pocket cost information, and to test for variability in charges amongst facilities and their potential impacts. The study concludes that: improved accountability mechanisms will eliminate information gaps; standardization will eliminate variability in extra billing; and extra billing sometimes leads to financial hardship, sub-optimal quality of life and negative health impacts for residents. Further study and pilot projects are proposed to determine the efficacy of free public provision of services.

Executive Summary

The Study Imperative

This is a preliminary examination of the range and cost of items and services billed to residents as "chargeable extras" in government-funded long-term care facilities in British Columbia.

Ongoing changes in the delivery of health care generally, and long-term care in particular, require policy makers to stay abreast of impacts of change to ensure efficiency and equity in service delivery. Recent changes relevant to this study include closure of long-term care beds; de-listing of many previously "insured" items/services, transferring payment responsibility from government to patients; and the new provincial access policy.

Strict eligibility criteria imposed in 2002 under BC's *Residential Care Access Policy* ensure that all residents have high and complex care needs resulting from multiple physical and cognitive deficits. Over seventy percent of residents are low income, many relying on Old Age Security (OAS) and Guaranteed Income Supplement (GIS) as their sole income source.

Lack of current, accurate data on out-of-pocket costs to residents in government-funded long-term care facilities is an information gap which will hamper government's ability to make policy decisions to maximize quality of life and health outcomes for residents, and minimize cost to the healthcare system. I found only two prior studies which included information on out-of-pocket costs for long-term care.

The 2002 Hospital Employees' Union report, *Profits Distort Priorities: Study of Long Term Care Facilities in British Columbia*, concluded that extra billing is widespread, and that there is great variability in billing practices amongst government-funded facilities serving similar clients. The study further suggested that more research is required to examine the question of variability in extra billing based on facility ownership type. Researchers hypothesized that increasing fiscal pressure on the long-term care sector could lead to more extra-billing over time.

Substudy # 5 of the *National Evaluation of the Cost-Effectiveness of Home Care* (Hollander, Chappell, Havens, McWilliams & Miller,2002) contained some information on out-

of-pocket costs for long-term care in Victoria, BC; but due to dramatic changes in the landscape of long-term care in the intervening five years, updated information is required to inform policy makers.

Objectives of the Study

The current study addresses the following questions:

- What is the most efficient and effective method of gathering information regarding out-of-pocket charges to residents of government-funded long-term care facilities in BC?
- Is there variability amongst government-funded long-term care facilities in the application of out-of pocket charges to residents?
- Are there significant differences in extra charges based on facility ownership (for-profit versus not-for-profit)?
- What are the potential impacts of out-of-pocket charges on
    - quality of life and health outcomes for residents?
    - costs to the healthcare system?

Methodology

Five data collection methods were employed:

1. interviewing key informants;
2. pricing health-care related items and equipment;
3. administering a telephone survey to staff at eight long-term care facilities;
4. collecting expense diaries and questionnaires from family members of four long-term care residents; and
5. comparing extra charges to residents of one facility over the three-year period from 2002 to 2004.

Problem Context

Accurate information is essential to inform government's policies on delivery of long-term care in a residential setting. A number of factors have contributed to the dearth of information regarding extra billing in BC's long-term care facilities.

Because community and long-term care are not subject to the *Canada Health Act*, and because facilities in BC are governed by two different provincial laws (The *Hospital Act* and the *Community Care and Assisted Living Act*), variability exists in billing practices amongst comparably funded facilities serving similar clients. Lacking reporting requirements and accountability/monitoring systems, the province is operating in an information vacuum regarding

extra billing practices in government-funded facilities. This information gap was acknowledged by Health Services Ministry and Vancouver Coastal Health managers in the study interviews.

Another contributing factor to the information gap is the difficulty of gathering meaningful data in the absence of a government reporting mechanism. The study found serious weaknesses in the methodologies available to gather information on out-of-pocket costs.

The information below summarizes the financial situation for most residents in long-term care, and points to potentially serious affordability problems due to the small amount of residual income available to residents after payment of facility per diems.

Resident per diems cover only a portion of the total cost of facility care, the larger share of which is funded by the province through reimbursement payments to the facilities. Seventy-two percent of residents fall into the lowest income category used to calculate facility per diems, and contribute eighteen percent of the cost of their care in the form of per diem payments. Those with the highest incomes (four percent of residents) pay per diems covering forty-three percent of the total cost.

October 2003 saw the first increase in per diem rates in BC since 1997, and beginning January 2004, residential care rates have been tied to the consumer price index. Effective January 2005, the per diem for the lowest income residents is $28.10, or $854.71 per month, while monthly income of the poorest residents – those who receive only Old Age Security (OAS) and Guaranteed Income Supplement (GIS) – is $1,032.45. Residual income after payment of the $854.71 per diem is only $177.74.

Residents pay standardized per diem charges based on a sliding scale according to their incomes; however the situation is far from standardized when it comes to additional out-of-pocket charges to residents. The current study focuses on this issue.

Conclusions

The study concludes that:

1. There is currently no efficient and effective method of gathering information on out-of-pocket charges in BC's government-funded long-term care facilities.
2. A wide variety of items and services are billed to residents over-and-above per diems, and there is great variability amongst facilities in the application of out-of-pocket charges.
3. More information is required before any conclusion can be reached regarding differences in extra billing practices or amounts of extra charges based on ownership type (for-profit versus not-for-profit).

4. Out-of-pocket charges are creating hardship for residents and their families, and may result in decreased quality of life and negative health outcomes for residents.
5. Out-of-pocket costs are unaffordable for low-income residents. More study is required to determine the efficacy of free-public provision of select items and services to lower overall healthcare costs.

Recommendations

Three recommendations flow from the study conclusions. They are put forward to address issues of gaps in information, accountability and consistency in long-term care delivery.

Recommendation # 1: that contractual reporting and accountability requirements for extra billing be written into funding agreements between health authorities and service providers, and that a monitoring system be designed and implemented.

Recommendation # 2: that the Ministry of Health Services standardize items and services provided without extra charge to residents of all government-funded long-term care facilities in BC.

Recommendation # 3: that the Ministry of Health Services commence controlled research trials in the form of pilot projects to inform policy on which items and services should be provided to long-term care residents without charge. (Two priority research areas/pilot studies should be: a) the efficacy of providing free hip-protectors as a method of reducing hip fractures, and b) a benefit/cost analysis of providing free dental care.

Dedication

This work is dedicated to Ethel Wait, Margaret Barclay, Maisie Shiell, Maureen Lehman, and Ella McDonald. I could always trust these five extraordinary "older" women to help and to inspire me. Throughout my life they variously filled the roles of playmates, colleagues, surrogate mothers, and teachers. Even in times of adversity, advanced age and failing health, their wisdom, dignity, grace, generosity, energy, humility and Joie de Vivre remained constant. I greatly love and admire these women, and my life's challenge is to follow their example.

Acknowledgements

Thank you to the many people who have helped me throughout my graduate studies. Thanks to the admissions committee for taking a chance on me as a mature student. Thanks to Karen McCredie, our capable MPP graduate assistant, for guiding me through the graduate school system; keeping me informed of requirements, deadlines, seminars, scholarships and bursaries; helping arrange department functions; and for her stalwart good humour and encouragement. Thanks to Dr. Nancy Olewiler for her help with financial aid applications.

Thanks to all my professors, in particular, to Professor John Richards for economics tutorials and for arranging and supervising my summer internship with AIBC. Thanks to Professor Aiden Vining for pointing me to some useful sources for the AIBC study and for assistance with editing the final paper. Special thanks to Professor Doug McArthur for sharing his extraordinary wit and wisdom in policy analysis and negotiations.

I am grateful for the help of Justin Smith, my talented economics tutor, and for the support of my economics "study buddies", Louella Mathias and Daljit Kang. Thanks to "Cat" Cheng for her work on the softwood lumber project. All the members of my MPP class were generous in helping me, and always available for sympathetic on-line chats in the middle of the night.

I thank the numerous people who contributed to this capstone paper by giving of their time, expertise, guidance and encouragement.

Thank you to my professors, Dr. Nancy Olewiler and Dr. Kennedy Stewart for acting as academic supervisors for the research. They have provided helpful direction from the time the research protocol was developed, through to final editorial comments. They helped me to set achievable deadlines, and were flexible when life events sometimes intervened to require extensions. Thank you to Professor John Richards for sitting on the panel for my capstone defence, and for helpful editorial advice.

Thanks to Dr. Margaret McGregor, Marcy Cohen, and Patricia Wejr for providing me the opportunity to participate in their study of out-of-pocket costs in long-term care under the auspices of the Economic Security Project study sponsored by The Canadian Centre for Policy

Alternatives and Simon Fraser University. I thank them for granting me permission to use information gathered in that study as part of my capstone project for inclusion in this paper. As my external research advisors, they have guided me to many helpful contacts and print resources and have inspired me with their expertise and research on behalf of long-term care residents and caregivers.

Thanks to Mary Beck for cheerful and professional assistance with telephone interviews, note taking, and data entry. Thanks to my husband, Don Gayton, for stepping in to assist with pre-scheduled interviews when I was called away for two weeks. Thanks to Michelle Cox for transforming data spreadsheets into manageable table formats.

The nine staff from eight long-term care facilities who completed caregiver surveys provided detailed and insightful information for analysis. Thank you to the proprietor and the accountant of the facility which provided me with three years' anonymous resident billing data to assist with a year-to-year comparison of costs.

The four case study volunteers who met with me and completed out-of-pocket expense diaries shared their very personal stories, and put a human face on the hardships faced by long-term care residents and their families. I was moved by the loving care and attention they provide to their family members, and their interest in improving the long-term care system. I was honoured to meet some of their family members living in facilities.

Administrators from the Provincial Ministry of Health Services, and from Vancouver Coastal Health met with me during the busy winter holiday period on short notice, and shared their knowledge of long-term care issues, and provided me with updated policy manuals and statistics. My thanks to Karen Archibald, Manager of Information and Policy of the Home and Community Care Division of the BC Ministry of Health Services; Linda Rose, Director of Directly-Operated Facilities for Vancouver Coastal Health; Linda Thomas, Director of Contracted Residential Care and Assisted Living Facilities for Vancouver Coastal Health; Nancy Rigg, Executive Director of the Community Care Network, Regional Office for Vancouver Coastal Health; and to Ed Helfrich, Executive Director of the BC Care Association.

Charmaine Spencer of the SFU Gerontology Centre provided me with helpful guidance in my literature review, and provided updated information on OAS and GIS rates for low-income seniors. Ian Forsyth, SFU Information and Privacy Co-coordinator pointed me to applicable Freedom of Information and Protection of Privacy Legislation. Laura Campbell, Acting Manager

of Client Affairs for the Public Trustee's Office, put forward my request for information from their client files.

Other researchers were generous in sharing information on their prior studies and ongoing work. These included Dr. Olena Hankivsky, Dr. Daniel Cohn, Dr. Jo Ann miller, Dr. Janet Fast, and Wendy Armstrong.

My lovely daughters, Anna and Jackie Gayton kept my life in balance, and were incredibly supportive of my graduate studies. They also assisted me with the retail pricing portion of the work.

Numerous people generously volunteered their time and expertise in face-to-face interviews, telephone interviews, and electronic communications. If I have omitted anyone who met with me or otherwise provided assistance, I apologize. Every contact provided me with helpful information and insight for the paper.

Any errors or omissions in the paper are the sole responsibility of the author.

Judy Harris

Table of Contents

List of Figures

List of Tables

1 Defining the Problem of Extra Billing in BC's Long Term Care Facilities

1.1 Study Imperative

This is a preliminary examination of the range and cost of items and services billed to residents as "chargeable extras" in government-funded long-term care facilities in British Columbia. These are items and services which are paid for out-of-pocket by residents or their families over and above basic per diem charges for room and board and basic care. A comprehensive literature review and consultation with researchers in the field confirmed that little information exists regarding out-of-pocket expenditures by residents and families of residents in BC's long-term care system.

Dramatic increases in the numbers of people in the over sixty-five age cohort, and more particularly the increases in numbers of people in the over eighty-five age cohort, mean that an increasing percentage of the population will require long-term care over time. Depending on eligibility criteria applied in a given jurisdiction, it is estimated that between five and twenty percent of the elderly population will be using long-term care in Canada at any given time. Many will be cared for in the community by family, friends and home-support services; but a certain percentage will require facility care. In 1991, Statistics Canada found that forty-six percent of the very old (eighty-five and older) live in facilities (Havens 2002, p. 96). This study relates to those in facility care.

Significant health-care reform is ongoing in British Columbia. In recent years there have been changes to insured services related to pharmaceuticals, physical and occupational therapy, optometry, and so forth. There has been a shift in financial responsibility from medical insurance plans to payment by individuals; residents of long-term care facilities have not been exempt from these changes. Concurrently, eligibility requirements for admission to long-term care facilities have become more restrictive, and per diem rates have increased.

Some long-term care facilities currently fall under the *Hospital Act*, while others are governed by the *Community Care and Assisted Living Act*, proclaimed in May of 2004. The two acts are inconsistent in regard to chargeable extras. *Hospital Act*-designated facilities provide

services to their long-term care residents similar to those provided to their acute care patients. Several types of therapy and such items as over-the-counter medications and special mattresses are not billed to patients in *Hospital Act*-designated facilities, but are billed in those falling under the *Community Care and Assisted Living Act.* Another significant difference in the two acts is that *Hospital Act*-designated facilities have no restrictions on extra room charges which can be imposed for "preferred" accommodation (such as semi-private or private rooms) as opposed to "standard" ward-style rooms with more beds. Room differential charges can exceed $25 per day in these facilities, whereas the upper limit for room differentials in facilities which fall under the *Community Care and Assisted Living Act* range between $3 and $9 per day, with caps strictly enforced for various categories of preferred accommodation, depending on number of beds, shared versus private lavatory and so forth.

There are legitimate grounds for concern that out-of-pocket costs could create financial hardship for facility residents, and that low-income residents, in particular, may be doing without medically necessary items and services. If this is the case, quality of life and health outcomes for residents could be negatively affected. This could result in increased financial cost to the healthcare system if residents forego necessary purchases and suffer adverse medical consequences requiring expensive treatment or admission to acute care.

Lack of accurate data regarding out-of-pocket costs to residents in government-funded long-term care facilities is a serious information gap which will hamper government's ability to make policy decisions to maximize quality of life and health outcomes for residents, and minimize cost to the healthcare system itself.

A 2002 research study conducted by the Hospital Employees Union of British Columbia reported that out-of-pocket charges are common in BC's long-term care facilities, and that there is no standardization regarding chargeable items and services (HEU, 2002, summary). The HEU study suggested that for-profit government-funded facilities charge for a greater range of items and services than their not-for-profit counterparts – that similar amounts of public funding are providing different levels of insured services to residents. The evidence also suggested that out-of-pocket charges are increasing in for-profit and not-for-profit facilities.

The HEU study concluded that more research into the prevalence and impacts of out-of-pocket expenditures is necessary, particularly in light of the significant healthcare reform which is under way as a result of funding constraints and demographic changes (Pitters, 2002, p. 169).

Subsequent to the HEU study, eligibility criteria for admission to BC facilities have been substantially revised, making them much more restrictive and resulting in an increased proportion of admissions of residents with complex, high needs. Most have cognitive as well as physical impairment, and multiple health problems. Higher needs can translate into additional out-of-pocket expenditures for residents and families.

Per diem rates have also increased, leaving residents with less disposable income after payment of base monthly charges. There was very little information available before all of the above-referenced changes were implemented; and the combined effects of the changes may have rendered that information irrelevant in the current context. This is an area which deserves more research focus because of the importance of the long-term care sector in the lives of a growing segment of the population.

Accurate data on the prevalence, variability and impacts of extra charges in BC government-funded long-term care facilities will be helpful to inform policy analysts, legislators, and providers of care as they move forward with ongoing healthcare reform. Determining efficient methodologies to gather accurate and meaningful information on out-of-pocket costs is an important component of this work.

1.2 Objectives of the Study

The current study addresses the following questions:

- What is the most efficient and effective method of gathering information regarding out-of-pocket charges to residents of government-funded long-term care facilities in BC?
- Is there variability amongst government-funded long-term care facilities in the application of out-of pocket charges to residents?
- Are there significant differences in extra charges based on facility ownership (for-profit versus not-for-profit)?
- What are the potential impacts of out-of-pocket charges on
    - quality of life and health outcomes for residents?
    - costs to the healthcare system?

2 Methodology

This study set out to test the efficiency and validity of several data collection methods. The dearth of existing information on out-of-pocket expenditures for long-term care residents suggested a hypothesis that data collection problems exist. Reasons for selecting the data collection methods in this study are explained below.

A literature review and five data collection methods were employed in this study. This section explains the procedures used for each research tool, and briefly describes the literature review and each research instrument's strengths and weaknesses. The five study methods were:

1. interviewing key informants;
2. pricing health-care related items and equipment;
3. administering telephone survey to staff at eight long-term care facilities;
4. collecting expense diaries and questionnaires from family members of four long-term care residents; and
5. comparing extra charges to residents of one facility over the three-year period from 2002 to 2004.

The literature review only identified two studies (Hollander et al., 2002 and HEU, 2002)which dealt directly with out-of-pocket costs for long-term care. Other studies, however provided evidence of negative consequences resulting from charging patients for medically necessary items and services.

Key informant interviews proved to be an efficient method of obtaining background information on current policies and procedures, and updates on provincial research initiatives. Detailed information regarding out-of-pocket charges could not be obtained using this method due to lack of facility reporting and accountability requirements.

The retail pricing of a number of medically necessary items and services shows the range of unit prices, and was done in order that unit prices could be matched with information provided by caregivers and family members regarding quantities/usage.

The telephone survey of caregivers was tested as a methodology as a follow up to the *Profits Distort Priorities* study (HEU, 2002). Results of the HEU study suggested that the practice of "extra billing" is widespread in BC's government-funded long-term care facilities, and that there is great variability in billing practices. The HEU study found some evidence that patterns of extra billing related to ownership type, with for-profit facilities charging for more items and services than their not-for-profit counterparts. The telephone surveys of caregivers for the current study were intended to build on the previous HEU work, and to provide a comparison to that study's findings.

The case-study methodology of collecting two-week out-of-pocket expense information in diary form was tested in this study as a follow-up to Substudy # 5 of the *National Evaluation of the Cost-Effectiveness of Home Care* (Hollander et al., 2002). The unique two-week expense diary methodology employed by Hollander et al. (2002) to collect out-of-pocket expense data was extremely labour-intensive and impossible to replicate in the current research, but a micro-application of the diary approach was selected as a data gathering tool in hopes that some useful comparisons could be made between the Holander data collected in 1999, and that gathered from current case study participants.

The comparison of extra charges from one facility over the three-year period from 2002 to 2004 was tested as a method of determining average billings to residents over time. As well, it was hoped that facility billing information could be compared to results from the study by Hollander et al. (2002), but because that data included out-of-pocket costs for items and services purchased outside the facility as well, no meaningful comparison could be made.

2.1 Literature Review

2.1.1 Data Bases and Key Word Search Terms

The scarcity of studies directly relevant to out-of-pocket costs of residents of for-profit and not-for-profit long-term care facilities was confirmed through a comprehensive literature search. Appendix A describes the data bases and search terms utilized in the literature review.

2.1.2 Criteria for Inclusion in the Literature Review

Emphasis in the literature search was on studies which met the following criteria if possible: Recent studies (preference for studies completed within the past five years); Canadian

studies (otherwise UK and N. America); focus on the frail elderly population; and focus on direct economic costs.

2.1.3 Themes Researched in the Literature

The literature surveyed encompassed several major related themes:

1. Facility Per Diem Charges for Long-Term Care (exclusive of extra charges)
2. Additional Out-of-Pocket Costs in Long-Term Care Facilities Borne by Residents, Families and Informal Caregivers
3. Effects of Cost-Shifting --User Fees/Co-payment on Access, Usage, Outcomes
4. Methodology for Determining Costs

Government costs for long-term care are available in literature and from government publications and websites, as are per diem rates for basic room, board and care in facilities. Only two sources were found which addressed extra (out-of-pocket) charges. Numerous sources related generally to cost shifting in the health care sector were reviewed, and nine were found to be most relevant to this paper. These are summarized in Appendix B. Methodology for determining out-of-pocket costs was only found in the HEU (2002) and Hollander et al. (2002) studies.

I contacted a number of experts in the field of long-term care for assistance in locating relevant studies. These researchers are listed in Appendix C. All confirmed the scarcity of literature related to out-of-pocket costs.[1]

2.1.4 Strengths and Weaknesses of the Reviewed Literature

There is very little literature which directly relates to out-of-pocket costs in long-term care facilities. Part of the problem in obtaining Canadian data is that residents of "institutions" are not included in the Census as members of households, so that costs for care of family members in long-term care facilities are mixed into miscellaneous expenditure categories such as

[1] Dr. Cohn confirmed that data on out-of-pocket costs in Canadian residential care settings doe not exist because of the way national data is gathered and accounted for by Statistics Canada. Once a person moves from the family home into residential care, Statistics Canada does not collect household expenditure data related to the "institutionalized" person who is no longer considered a member of the household. Dr. Fast indicated that the data in Substudy # 5 remains the most current and rigorous available, even though it was gathered in 1999.

"gifts". The literature search did not identify any direct studies on out-of-pocket costs for long-term care in other jurisdictions.

The comprehensive study by Hollander et al. (2002) contains only a small amount of data related to out-of-pocket costs, and is over five years old. A strength of that data is that facilities in BC were sampled, but the study methodology (which incorporated, among other tools, two-week diaries completed with assistance of a large number of paid staff) is extremely difficult and costly to replicate. For-profit and not-for-profit facilities were not differentially coded for data analysis in the work of Hollander et al. (2002), so a comparison of the two ownership types was not possible from that study.

This study cannot corroborate the HEU results (HEU, 2002) since no significant differences were found in extra billing based on ownership type, and different methodology was employed (fewer facilities sampled, fewer staff surveyed, no focus groups conducted). A reliable comparison of the current survey results to the HEU study is not possible.

Only three of the co-payment studies sampled large numbers of frail elderly, and none were specific to those in residential care. Many of the studies related to impacts (including unintended adverse health effects) of increased co-payments or charges, but did not deal with the target population of frail elderly residents of long-term care facilities. Several of the more recent studies from Canada documented impacts on asthmatic children, for example. Other studies document negative impacts of co-payment for anti-psychotic medication. Results of all of the studies showed an inverse correlation: Increased client cost correlated with decreased use of necessary medication and/or treatment. The literature provides fairly strong evidence that cost matters, and it is reasonable to assume that the correlation would hold for the frail elderly residents of BC's long-term care facilities who are the focus of this study.

Most studies found in the literature on the impact on family caregivers dealt with home and community care situations, or non-monetary costs such as stress, family discord, and adverse effects on informal family caregivers' health (Armstrong, 2002).

2.2 Interviewing Key Informants

The names and positions of key informants interviewed are found in Appendix D. Three interviews were conducted in person, and two by telephone.

2.2.1 Strengths and Weaknesses of Elite Interview Methodology

Elite interviews of Vancouver Coastal Health and Ministry of Health administrators were extremely useful and efficient research tools. Interview information helped validate the results and analysis of other instruments such as the caregiver surveys by confirming that government and health authorities acknowledge wide variations in policy and practice around extra-billing in long-term care faculties.

Interviewees also provided copies of current BC policies, and explained initiatives to work toward standardization and fairness amongst facilities. Details of policies and practice within individual facilities could not be gleaned from these interviews; managers acknowledged that they do not have an accountability mechanism yet in place to require facilities to report on extra billing. Health Ministry block funding of facilities provides flexibility, but reduces accountability regarding extra charges to residents. Extra billing information is only examined upon complaint or audit.

2.3 Pricing Healthcare Related Items and Equipment

A range of prices for numerous health-care related items and equipment was developed by pricing retail items in person at retail outlets, by viewing on-line catalogues, and by obtaining telephone quotes. Details of pricing sources are found in Appendix E. Prices are found in Appendix F.

2.3.1 Strengths and Weaknesses of Retail Pricing Data

The price lists provide the range of retail cost for items which have to be paid for by residents. However, on their own, unit prices don't mean much, because each resident's needs and usage are unique. It is one thing to document the price of dressings or medications, but without knowing an individual's usage, the unit prices are insufficient to determine out-of-pocket cost. Cost per unit and quantities purchased are required. Combined with caregiver survey responses regarding client usage rates, and the detailed itemization of costs from the family expense diaries, a picture begins to emerge of what might be typical costs for many residents. For those with mobility impairment who also require very costly specialized wheelchairs, cushions, mattresses, hip protectors, and so forth, the commonly incurred costs based on the range of retail unit prices in the list provide helpful supplementary information.

Missing from the price lists are the costs of items/services such as optometry and prescription lenses, dentistry and denturist services, dentures, hearing aids and other prostheses. Needs for these items and services are unique to each resident, but are commonly required by frail elderly residents (as documented in the diaries, surveys and literature), and can represent significant expenditure outlay. To fill in these gaps, selected price estimates for dentures, eye examinations, and prescription eyeglasses were obtained from several Vancouver sources.[2] 2003 Hearing aid price ranges were obtained from the website of the BC Association of Speech/Language Pathologists and Audiologists.

2.4 Administering Telephone Surveys to Facility Caregivers

A telephone survey, conducted as a follow-up to a previous HEU study, was administered to a nine caregivers from four for-profit and four not-for-profit facilities in the Greater Vancouver area of BC, to ascertain: what items and services are charged to residents; whether or not these charges create hardship to residents and their families or negatively impact quality of life and health outcomes of residents; and whether or not extra billing practices had changed since 2002. Methodology for recruiting survey participants and conducting interviews is documented below.

2.4.1 Selecting Facilities

Lower mainland facilities were chosen through both non-random and random selection. The non-random selection included four (two for-profit and two not-for-profit) facilities from the prior 2001 surveys conducted for the Hospital Employees Union study (HEU, 2002,) The randomly selected facilities were drawn from a list of facilities located in the Lower Mainland where staff are unionized by the Hospital Employees Union and the BC Nurses Union (BCNU). Two randomly-selected for-profit facilities were matched as closely as possible with two non-profit facilities with similar characteristics for size and case mix.

2.4.2 Recruiting and Interviewing Survey Volunteers

A letter of invitation from the relevant union was sent to the home address of each potential participant. Professional and direct care staff in the job classifications of patient care

[2] Eye examination and prescription lenses estimate from West End Optometry. Denture cost estimates from Vancouver Centre Dental Clinic (based on BC Dental Assoc. Fee Guide), and from Denman Denture Clinic.

aide, registered nurse, licensed practical nurse, social worker and pharmacist were approached to complete a survey questionnaire on items and services charged to residents in their facilities.

Those who wished to participate returned written confirmation of their willingness to be interviewed, and were mailed detailed consent forms and a copy of the survey which would be administered by telephone interview. The volunteers were then contacted by phone to arrange a convenient time for the interview. Whenever possible two researchers participated in the interview to ensure accuracy in note-taking.

2.4.3 Strengths and Weakness of Caregiver Telephone Survey Methodology

There were several weaknesses in the caregiver survey methodology, the first of which was the low response rate from invitations sent to staff, inviting their participation in the study. It was hoped that a minimum or three or four staff from each of the eight facilities would agree to complete the telephone survey. For reasons of ethics protocols and confidentiality, it was impossible to determine why many invited participants chose not to respond. Several plausible explanations exist, including the fact that staff are extremely busy. Some may have feared reprisal from employers if it became known that they participated in the study; others may have been angry at their unions or employers following the settlement of a very acrimonious contract dispute in 2003. Invitees may have questioned the purpose of the study or the value of their participation. There was no way to determine why the response rate was lower than anticipated.

In the only facility which had two respondents independently complete the survey, some of their answers were contradictory. This could call into some question the reliability of answers from the other survey participants, each of whom was the sole participating staff member from a particular workplace. There were also a large number of "don't know" responses to questions regarding charges for particular items or services.

Added to problems of the small sample size and possible reliability issues described above, the "don't know" responses made comparison of the two ownership types difficult, especially when a larger percentage of one type than the other responded to a given question. This was a significant problem because of the small sample size, and calls into question the validity of comparison of billing practices for-profit and not-for-profit facilities for many billing categories. Nine of twenty billing categories contained missing answers from one or more of the eight study facilities.

Another serious problem with the survey tool was that I was unable to develop a rational and defensible weighting formula to take into account the relative cost of specific items and

services, or their relative importance in terms of potential health outcomes and/or net cost to the health care system. Therefore no weighting of any kind was applied, and this deficiency in methodology confounded the analysis of the caregiver survey information in relation to the study questions. Unit costs of surveyed items and services range from pennies to many thousands of dollars. Resident charges for some items and services may be construed to be less critical for health outcomes (possibly hairdressing, for example), whereas charges for other items and services (such as laxatives and hip protectors) may potentially have extremely serious health and budgetary implications.

Findings from the former HEU study suggested that for-profit facilities tended to charge greater amounts for more items and services than not-for-profits. One of the purposes of this study was to follow up on findings of the prior HEU work. Results of the current study are inconclusive regarding patterns of extra billing by facilities based on ownership type. Due to differences in study methodology (the current study had a smaller sample size and did not include focus groups), direct comparison of results is not possible.

Responses whether or not there had been changes in billing practices between 2002 and the time of the current study were difficult to interpret without reference to specific comments or free responses. As with the insured coverage questions, there were numerous "don't know" responses which made generalization difficult, and rendered comparisons between facility types invalid.

In some instances changes in billing represented a new benefit to residents (i.e. a change from charging for an item or service to providing it without charge), and others represented a new cost (i.e. a change from providing an item or service without charge to charging residents).[3] Therefore results must be interpreted with caution. Reported change represents a change in either direction, increased or reduced coverage. *As well, readers should be cautioned that the responses only relate to whether or not billing practices have changed since 2002, and NOT whether or not the item or service in question is charged to residents. A response indicating no change could mean the item was provided without charge in 2002 and continues to be supplied free of charge, or, conversely, that the item was charged to residents in 2002 and continues to be a chargeable item.* All that the responses document is whether or not there was a change in practice. Therefore

[3] For example, subsequent to 2002 one for-profit facility began providing laxatives, enemas and suppositories in the bowel care category to residents without charge after they determined their previous policy of charging for items was resulting in under use which was causing a high rate of adverse health effects and increased acute care admissions for impactions.

the information cannot be properly interpreted without reference to the comments or free-response sections of the survey.

Free response sections of the surveys were very helpful, and allowed participants to elaborate on issues of importance and to provide concrete examples. As explained above, the free responses also clarified many ambiguous answers.

2.5 Collecting Expense Diaries and Questionnaires from Family Members

Members of two family councils for facilities in the lower mainland were approached (one through a written request to a council meeting and the other in-person at a council meeting) and asked to volunteer to complete questionnaires and two-week expense diaries. One volunteer was recruited through the written request, and three were recruited through the verbal presentation. Volunteers were mailed consent forms and copies of the questionnaires and diaries to complete and return by mail.

2.5.1 Strengths and Weaknesses of Expense Diary/Questionnaire Methodology

I was unable to recruit more than four volunteers, partly due to the unfortunate timing of the data collection, which had to be completed between Christmas and the end of January due to external study time constraints. Three additional family council members contacted me to apologize that they were too busy to participate in the research in spite of their interest in helping with the study. Research questions also required volunteers to provide personal information regarding the health and finances of their family members, and although anonymity in the final report was guaranteed, some potential volunteers may have been uncomfortable sharing personal information of that nature with a student researcher. All four volunteers completed the two-week expense diaries and questionnaires.

The shortcoming of using a small number of non-random case studies is that results cannot be generalized or assumed to represent "typical" expenditures for the larger population of long-term care residents. The case studies were extremely valuable, however, in documenting real costs to four residents and their families. They provided detailed real-world examples of actual, rather than theoretical, costs to residents who share a number of common characteristics with many other long-term care residents. The in-depth analysis of the cost of care for four residents and their families provided evidence that, at least for these four residents, per diem rates do not cover items and services which some family members deem necessary to optimize quality

of life and health outcomes for their loved ones. The case studies serve to put a human face on the issue, familiarize the reader with the types of situations and costs encountered by some families and residents, and provide more detailed information than is ordinarily obtained through statistical analysis or other research methods. Although these four individual case studies cannot be used in isolation to draw general conclusions, they are useful to help frame research questions for further study.

2.6 Three-Year Cost Comparison of Out-of-Pocket Billings

Billings to residents of one proprietary, for-profit long-term care facility were compared for the years 2002 to 2004. For each of the three years the facility provided financial records detailing all billings to residents from the pharmacy, as well as all charges against resident "comfort" funds for other items and services paid for by residents.

2.6.1 Strengths and Weaknesses of 3-Year Billing Comparison Methodology

The three years of resident billings from one facility provided a general overview of the types of items and services charged to residents. Not knowing the use of funds in the Cash Withdrawal category was a serious limitation. Average costs must also be analyzed with great caution, since billings for individuals with different needs varies significantly. In spite of the shortcomings of the aggregated billings, certain trends, such as dramatic increases in pharmacy charges, provide evidence that further, in-depth, longitudinal study of resident charges is desirable.

A shortcoming of the billing data is that it does not capture additional expenditures on behalf of residents for items/services purchased outside the facility or brought into the facility but invoiced directly to residents by outside providers. Therefore it is important to remember, and to consider the residents' typical costs for items such as hearing aids, prescription lenses, dental work, dentures, and mobility aids, which do not appear on facility billing records. Extra services such as physiotherapy, massage, music therapy and so forth are also absent from identified billing categories, leading to questions regarding access to and cost of these services, which are commonly required by frail elderly residents of long-term care facilities.

2.7 Conclusion

None of the five data collection methodologies employed in this study is sufficient on its own to provide reliable out-of-pocket cost information to answer the study questions. Taken

together, the information gathered from all five methodologies provides a clear picture that there is substantial variability amongst facilities in extra billing practices and that extra billing may adversely impact quality of life and health outcomes for residents. No conclusion could be made regarding variability of extra charges based on facility ownership type. Minimal information on potential costs to the healthcare system was provided in a few caregiver surveys, and was inferred from previous studies cited in the literature review regarding such things as falls and hip fractures, impacts of poor dental health, and decreased usage of medically necessary pharmaceuticals or other items and services based on co-payments. My conclusion is that the methodologies employed in this and other prior studies are inadequate to inform policy makers, and that this information gap may hamper government's ability to provide the most efficient and effective delivery of long-term care.

3 History and Current Context of the Problem

This section reviews the regulatory, demographic, and fiscal context in which BC's government-funded long-term care facilities operate. Variability in extra billing is explained in relationship to legislative and definitional ambiguity. Demographic trends, fiscal constraint, and regulatory changes will be discussed as contributing to the problem of extra billing. Eligibility criteria for admittance into long-term care are explained, as are resident per diem calculations which determine, based on income, the client's portion of the cost of facility room and board and basic care. This information is used to discuss the very minimal remaining income available to low-income residents for purchase of all other medically-necessary items and services, and other living costs and discretionary expenditures.

Significant previous studies are cited to illustrate potential harmful and costly impacts of unaffordable out-of-pocket costs for medically-necessary items and services. This section puts into context, the research results discussed in subsequent chapters.

3.1 Vulnerability of the Publicly-Funded Long-Term Care Sector

Community and Continuing Care, whether provided in the home, or in long-term care facilities, falls outside the jurisdiction or the *Canada Health Act*. Without the protection afforded by the *Canada Health Act*, dramatic changes to, or elimination of long-term care services can be made by government as a matter of policy.

> It [the sector] lacks both stability and status, falling as it does outside the current interpretation of the *Canada Health Act*. Services, user fees, eligibility criteria, delivery structures and core funding can be changed and/or eliminated by an administrative order or policy shift at any level" (CCPA, 2000, *Without Foundation*, Summary, p. 1).

Without the force of the Act, there is no assurance that residential long-term care (or home care, for that matter) will be affordable, accessible, publicly administered, portable, or universal (Havens, 2002, p. 104). Whether or not long-term care should be brought under the protective umbrella of the *Canada Health Act* is beyond the scope of this study. The fact that long-term care does not fall under the purview of the *Canada Health Act* is contextually

significant, however, because this is what provides the flexibility for provinces to determine which items and services will be partially or fully-covered under their respective health insurance programs. Moving to include long-term care in the definition of insured health services within the *Canada Health Act* has serious tax and budget implications beyond the scope of this paper.

3.2 Canada's Aging Population

The effects of population aging in Canada are the subject of a large body of literature, and the focus of many research studies. The demographic shift is dramatic, and has led to dire predictions – sometimes referred to as "apocalyptic demography" – of the collapse of social programs such as the Canada Pension Plan and healthcare system due to the increased demands which will be placed on those programs as the baby boom generation moves into old age (Gee and Gutman, 2000, introduction). Others laud the aging population as a success story resulting from advances in nutrition, medicine and healthcare which enable people to live longer and in better health than ever before. Adherents to this viewpoint assert that the negative implications of population aging have been oversold (Gee and Gutman, 2000, introduction).

The shifting demographic trends are dramatic, particularly when disaggregated into specific age cohorts. The following is an excerpt from a table produced in the Canadian Policy Research Network's research report F|35 (Jensen, 2004. p. 6). The data from 1941 to 2001 show that the fastest growing demographic was those older than eighty, exhibiting a forty-one percent increase. Statistics Canada predicts that in 2011, the number of the "oldest of the old", those over eighty, will reach 1.3 million (Jensen, 2004. p. 10).

Table 1: Percentage of Elderly Canadians by Age Cohorts by Decade, 1941 -2001

Demographic	1941	1951	1961	1971	1981	1991	2001
Population over 65 as a percent of total population (Health Canada (2000)	**6.7**	**7.8**	**7.6**	**8.0**	**9.6**	**11.4**	**13.0**
Population over 85 as a percent of the population over 65	**4.7**	**4.8**	**5.8**	**7.9**	**8.2**	**9.8**	**10.7**

Data Source: Jensen, Jane. "Catching Up to Reality: Building the Case for a New Social Model" CPRN Social Architecture Papers Research Report F|35, Family Network. January 2004. p. 6

Statistics Canada projects a population increase for the total population between 1991 and 2031 of fifty-one percent, while the population aged sixty-five and over is expected to increase by 181.9 percent over the same time period.

Table 2: Percentage of Elderly Canadians by Age Cohorts, Actual 1991 and Projected to 2031[4]

Age Cohort	% of Total Population in 1991	% of Total Population in 2001	% of Total Population in 2021	% of Total Population in 2031
65+	**11.6**	**12.7**	**17.8**	**21.7**
65-74	**6.9**	**6.9**	**11.0**	**11.8**
75-84	**3.6**	**4.3**	**5.5**	**7.2**
85+	**1.0**	**1.5**	**2.4**	**2.6**

Data Source: Havens, Betty. Users of Long-Term Continuing Care In *Continuing the Care. p. 95.*

3.2.1 Disability Associated with Advanced Age

Although many argue that the elderly are healthier than ever before, there is still a direct correlation between disability and very advanced old age. The Health and Activity Limitation Survey (HALS) conducted by Statistics Canada in 1991 documented the number and percentage of persons with disabilities in Canada by Age and Residence. Although this research is now fourteen years old, it none-the-less illustrates the relationship. More recent Statistics Canada data from the year 2000 indicate that more of the institutionalized elderly are members of the oldest age cohort (Havens, 2002, p. 102). The Statistics Canada research indicates that although there has been a relatively dramatic increase in life expectancy for Canadians at ages sixty-five and eighty, these increases have not held for disability-free life expectancy. The following data was taken from page 97 of the Havens piece:

Table 3: Number and Percentage of Older Persons with Disabilities by Residence, 1991

Age Group	# Living in own Households	% Living in own Households	# Living in Facilities	% Living in Facilities	Total Number (100%)
65-74	**698,830**	**95.4**	**33,885**	**4.6**	**732,715**
75-84	**424,800**	**83.6**	**83,035**	**16.4**	**507,835**
85 & over	**112,315**	**53.9**	**96,000**	**46.1**	**208,325**

3.2.2 Number of Residents in Facility Care

BC's residential care facilities currently house approximately 25,000 British Columbians. At any given time 5,000 residents live in long-term care facilities within the Vancouver Coastal Health Authority jurisdiction (N. Rigg, personal communication, January 6, 2005).

[4] This figure for the % of population over 65 in 1991 is slightly different from the figure in the previous table from Jensen's paper because it was compiled from a variety of sources. Jensen's figure is 11.4% and Haven's is 11.6%. I don't know which is the accurate figure.

3.3 Rising Healthcare Costs

Healthcare cost and delivery implications of the increase in the numbers of the "oldest of the old" are of great concern. Every Canadian province and territory is struggling with rising costs of healthcare. In the fiscal year 2003/04, the British Columbia government spent over $10.7 billion on healthcare, which now comprises over forty-two percent of the total provincial budget (BC Health Services. 2004, *Today and Tomorrow*, pp. 1-2). The aging population in BC is placing additional cost pressure on the provincial healthcare system. Historically the elderly have disproportionately higher utilization rates for healthcare services. In 2001, for example, the average healthcare spending for persons sixty-five and over in BC was approximately 5.4 times greater per person than spending for those under sixty-five (Robson, 2001, p. 4). The Urban Futures Institute projects dramatic increases in provincial healthcare spending on all age groups, but much greater increases for the over sixty-five age cohort. After forecasting increased spending for all age groups, the study predicts:

> These increases all pale in contrast to the increase in spending on the 65 plus age group. In 1998, provincial health spending on this age group totalled $4.3 billion: by 2021, under the assumption of constant age specific health per capita spending and in constant dollars, total spending on the 65 plus age group will be $8.0 billion – the same amount that is currently spent on all age groups in the province. Aging will mean that every year from 2021 on, the provincial health budget for people 65 and older will be greater—in constant dollars—than its total health budget is today (Urban Futures, 1999, abstract).

3.3.1 Multiple Ownership Types for Long-Term Care Facilities

There are a number of ownership types by which long-term care facilities can be categorized. Figure 1 provides a definition of the various ownership types.

Figure 1: Categories of Long-Term Care Facilities in Canada by Ownership Type

Categories of Long-Term Care Facilities in Canada by Ownership Type

- **proprietary** – owned by an individual or corporation, and operated for profit;
- **religious** – owned and operated by a religious organization on a non-profit basis;
- **lay/charitable** – owned and operated by a voluntary, nonreligious, nongovernmental body on a non-profit basis;
- **municipal** – owned and operated by a municipality, city or town on a non-profit basis;

- **regional** – owned and operated by a regional health board or authority;
- **provincial/territorial** – owned by a branch, division or agency of a provincial or territorial government;
- **federal** – owned and operated by a department or agency of the government of Canada (e.g., Veterans' Affairs, Health and Welfare Canada).

Source: Alexander, 2002. p. 24.

Long-term Care Facilities in BC include beds in acute care hospitals, private hospitals, extended care hospitals, personal care homes, family care homes, intermediate care homes, multilevel care facilities and group homes. BC, like other provinces, has a long history of mixed ownership of long-term care facilities. A 1994 study found that over fifty-five percent of long-term care facilities in BC were in the for-profit sector, as was the case with Ontario, New Brunswick, Prince Edward Island, Nova Scotia and Newfoundland (Pitters, 2002, p. 191).

3.3.2 Revised Care Level Assessment Tool and Nomenclature

Another change which introduces some confusion into the current discussion of long-term care, is the gradual change-over to a new assessment tool and nomenclature regarding care levels. The BC Health Ministry is moving away from the current care level classification system which has been in place since the mid-1970s. Care levels were categorized as: personal care; intermediate care 1, 2, & 3; extended care, and so forth. Implemented in 2002, revised eligibility requirements for entry into facility care under the Provincial Residential Access Policy (PRAP) eliminated clients who formerly fell under the IC1 and IC2 designations (BC Ministry of Health, 2000, *Strategic directions).* Now all facility residents are those with higher levels of care

requirements, and are categorized as "complex care". The IMDS functional assessment tool for Facility Residents will be put into place starting in 2007.

3.4 Multiple Provincial Acts Regulating Long-term Care Facilities in BC

To further complicate matters, even though the residents of some of the various facility types are identical in terms of the level of care required, facilities fall under different legislation – some under the *Hospital Act*, and *Hospital Act Part 2*, and others under the *Community Care and Assisted Living Act,* which replaced the *Community Care Facility Act.* One of the inequities in the cost of long-term care to residents in the BC system stems from the fact that in facilities which fall under "hospital" legislation, items such as over-the-counter medications are fully insured – that is, provided to residents without charge. This is not the case in other long-term care facilities. This inequity violates the principle of horizontal equity, the provision of like services for the same cost to citizens in similar circumstances with similar ability to pay.

Adding yet another level of complexity, is that fact that the *Community Care and Assisted Living Act* – proclaimed on May 14, 2004 – contains sections pertaining to the regulation of private hospitals and public extended care facilities currently licensed under the *Hospital Act.* These sections of the new legislation have, at this writing, not yet come into force. The proposed regulation of these private hospitals and public extended care facilities (currently licensed under of the *Hospital Act*) is likely to move forward pursuant to Section 12 of the new legislation sometime in 2005/06, pending the outcome of current consultation and planning exercises (Archibald, 2005). As things currently stand, "Extended Care Facilities" (including denominational facilities) fall under the *Hospital Act, Part 1*; "Private Hospitals" fall under the *Hospital Act, Part 2*; and "Licensed Community Care Facilities" fall under the new *Community Care and Assisted Living Act*, which also regulates Assisted Living Facilities.

3.5 Implications of Inconsistent Legislation Governing Resident Charges

The BC government enacted Section 12 of the *Community Care and Assisted Living Act* in recognition of the need to standardize the regulation of facilities which currently provide government-funded residential care to similar clients, while charging residents different rates for such things as over-the-counter medications and room differentials, and providing different base services. Several of the differences in insured services were itemized earlier in this paper.

The amount residents will be charged for identical items depends, in many instances, on pure chance – where a bed happens first to become available when a client is deemed eligible for placement in residential care. Residents are placed in the first available appropriate bed, so only about forty percent of placements are initially in the client's preferred facility (L. Rose, personal communication, December 21, 2004). This violates the principle of horizontal equity in provision of equivalent government services at the same cost to citizens with similar ability to pay.

3.6 Ministry Recognition of the Problem of Variability in Extra Charges

In recognition of the lack of standards for chargeable extras in government-funded residential care facilities serving similar clients, the BC Ministry of Health struck a task force called the "Optional Goods and Services Working Group" in 2003. The committee includes representatives from every Health Authority in the province. They were charged with identifying inconsistencies, and at the end of 2004 had drafted a "Revenue Generation Policy" for internal review by the Ministry. The draft policy, which is not public information at the date of this writing, outlines what items and services must be included in facility per diems, and which are chargeable extras (K. Archibald, personal communication, January 5, 2005).

The Working Group did not address the issue of pharmacy charges, which Ms. Archibald, Manager of Information and Policy for the Home and Community Care Division, describes as "huge and difficult." She indicated that, in her view, it could take another three years of work to draft a new policy regarding pharmacy charges (Archibald, 2005). The current draft policy concentrates on standardizing what must be provided in terms of supplies and equipment, and standardizing room differentials.

3.7 De-listed Services Created Additional Variability in Insured Services

As part of a comprehensive budget restraint package, effective January 2002, the BC government de-listed a number of previously insured services such as physiotherapy, podiatry, optometry, chiropractic, naturopathy and massage therapy. These were de-listed for the population as a whole (with certain exceptions for children and other specific groups), including residents of most long-term care facilities. The Health Ministry is currently reviewing this policy regarding its application in long-term care facilities due to the higher levels of care required by residents resulting from tighter eligibility requirements and the larger number of very elderly

residents with high "acuity" levels requiring complex care. There is some discussion within the Ministry that, in future, physiotherapy, occupational therapy, and social work services will become insured services, provided at no extra charge in government-funded long-term facilities. They are currently only insured services for clients assessed at the highest acuity levels (Extended Care under the old nomenclature system).[5]

Analysis of what items and services should be covered under the provincial health insurance plan suffers from the lack of data on impacts of resident charges for services. Under the pre-2002 rules, more services were fully-insured, particularly for residents with high needs. Since the implementation of PRAP, *only* those with very high and complex needs are admitted to long-term care. There may be adverse health outcomes associated with the de-listing of therapeutic services which cost the health care system more than the savings derived from de-listing the service. Unintended costs need to be studied to determine the most efficient health care strategy for the high-acuity residents in long-term care (Archibald interview).

3.8 Higher Acuity Levels in Residential Facilities

As previously discussed, in April of 2002 the BC Health Ministry adopted the Provincial Residential Access Policy (PRAP). The intent was to shift long-term care service delivery as much as possible from residential care to home-based services. Access to residential care is now restricted to clients with very high healthcare needs. Besides meeting other eligibility criteria, those admitted to facility care must be assessed as requiring "complex care". In summary, the policy contains five major groupings for complex care:

1. A person who has severe behavioural problems on a continuous basis. The person may or may not be independently mobile (ambulant).
2. A person who has cognitive impairment, ranging from moderate to severe but who is socially appropriate. The person may or may not be independently mobile with the use of ambulatory aids.

[5] Another significant change, is that the health ministry is moving away from the current care level classification system which has been in place since the 1970s. Care levels were categorized as: personal care; intermediate care 1, 2, & 3; extended care, and so forth. Changes to eligibility requirements for entry into facility care eliminated clients who formerly fell under the IC1 and IC2 designations. Now all residents are categorized as "complex care", and by 2007 the new "IMDS system, which is a functional assessment tool.

3. A person who has cognitive impairment, ranging from moderate to severe but who is socially inappropriate. The person may or may not be independently mobile with assistance.
4. A person who is physically dependent but cognitively intact with medical needs that require professional nursing, and whose condition requires a planned program to retain or improve functional ability.
5. A person who is clinically complex; for example, a person who has multiple disabilities and/or medical problems that require professional nursing care or who has complex medical conditions that require monitoring and specialized skilled care.

Data from the Performance Management Branch of the BC Ministry of Health Services shows the immediate and very significant impact that the implementation of PRAP had on the profile of clients entering residential care. Ninety percent of persons entering BC's residential care facilities in 2002/2003 were categorized as intermediate Care Level 3 (IC3) and Extended Care (EC) – the highest care levels under the old nomenclature – up from sixty-eight percent in 2001/2002 (Crawford, 2003, pp. 40-41).

Higher acuity levels relate directly to the need for more medication, therapy, supervision, and specialized equipment. Low-income residents with severe mental and physical impairment are likely to have affordability problems if needed items and services must be paid for out-of-pocket. This relates to the study questions in that inability to purchase these items and services may decrease quality of life, create adverse health outcomes, and could (as in the case of hip protectors, for example) increase costs to the health care system.

3.9 Inclusion of Community Support in Assessment Criteria for Facility Admission

To determine eligibility for facility admission, Health Authorities are required to perform a standardized assessment (BC Ministry of Health Services *Standardized Assessment).* The need and urgency for residential care is not based on functional and risk assessment of the client in isolation from other factors. Two key considerations in the standardized assessment are: "a review of existing services provided to the client and/or caregiver; and a determination that services being provided and available resources cannot meet the client's needs or provide appropriate caregiver support."(BC Ministry of Health Services, *Standardized Assessment)*

Demographics of those entering care indicate that most are poor, single women whose healthcare needs are beyond the scope of what community caregivers, including any remaining family and friends, can provide. Evidence from caregiver surveys and family expense diaries in this study shows that when resident income is insufficient to purchase necessary items, family members often provide for needed purchases. The BC PRAP criteria actually create a selection bias in favour of residents lacking family support or other resources, which means that the majority of residents have no alternate source of funds to supply things they cannot afford on basic OAS/GIS income.

3.10 Calculation of Basic Facility Per Diem

Daily rates for basic accommodation, meals and care are calculated based on residents' "Remaining Annual Income." This figure is determined by deducting income tax paid (line 435 of the federal income tax return), and personal deduction applicable based on whether the resident is single or has a spouse, and earned income (up to $15,000/person) from the resident's net income from line 236 of the income tax form. If the resident has a spouse living outside the facility, the lesser of two calculations – one using "family income" and the second using only the resident's income – determines the rate.

These per diems cover only a portion of the total cost of facility care, the larger share of which is funded by the province by way of "reimbursement" payments to the facilities. Seventy-two percent of residents fall into the lowest income category, and contribute eighteen percent of the cost of their care in the form of per diem payments. Those with the highest incomes (four percent of residents) pay per diems covering forty-three percent of the total cost. October 2003 saw the first increase in per diem rates in BC since 1997 and beginning January 2004, residential care rates have been tied to the consumer price index. Effective January 2005, the per diem for the lowest income residents (remaining annual income up to $7,000) is $28.10, or $854.71 per month. The highest rate .per diem for residents with remaining income exceeding $30,000, is $67.50, or $2,053.13 per month (BC Ministry of Health Services, 2004, *HCC Fees,* p. 2).

The following table from 2003, although two years old, is useful because it summarizes the then-current monthly charges for standard accommodation in BC facilities and explains the method of calculating the sliding scale charges to residents.

Table 4: Charges to Residents in Facility-Based Long-Term Care in BC

Income/Asset Definition	Monthly Charges for Standard Accommodation	Variation of Charge with Income	Drugs	Medical Supplies and Equipment
Income test definition: Based on "Net Income" (line 236) less income taxes paid (line 435) and income deductions of $10,284 single and $16,752 couple; less first $15,000 of earned income. Remaining annual income is linked to rate codes. No asset test and no requirement to spend down assets.[6]	(Range of charges geared to income) Minimum : $27.10 per day = $824.29 per month Maximum $65.00 per day = $1,977.08 per month *Rates are adjusted annually in January based on Consumer Price Index.*	Minimum charged to those with remaining annual income of $7,000 or less or those on GIS. Maximum charge to those clients with remaining annual incomes over $30,000. 72 percent of residents in lowest income category. 4 percent of residents in highest income category.	Prescription medications in provincial formulary are covered under Pharmacare Plan "B" Over-the-counter medications provided without charge in facilities under Hospital Act; paid by resident in other facilities	Routine treatment supplies are covered. Client is responsible for equipment for own exclusive use (e.g. walker, crutches, wheelchair, cushions, hip protectors)

Source: MHR website: http://mhr.gov.bc.ca/publication/Vl1/Part7/7-15..htm

Residents pay standardized per diem charges based on a sliding scale according to their incomes; however the situation is *far* from standardized when it comes to additional out-of-pocket charges to residents. The current study focuses on this variability in extra billing amongst government-subsidized facilities, and the potential impacts of extra billing on residents and the health care budget.

3.11 Remaining Income After Payment of Per Diem

As documented by the BC Ministry of Health Services, the vast majority of long-term care residents (seventy-two percent as of October 2003) fall into the lowest income range. When disposable income is calculated after residents have paid basic charges, very little is left over for extras of any kind. Effective January 2005, the income of the poorest residents -- those who receive only old Age Security (OAS) and Guaranteed Income Supplement (GIS)—is $1,032.45. Remaining income after payment of the $854.71 per diem only leaves $177.74 to cover all other living expenses (C. Spencer, personal communication, March 7, 2005).

[6] There is an interesting problem associated with out-of-pocket purchase of expensive, medically necessary items such as specialized wheelchairs (which can cost up to $6,000.00) or a special mattress (which can cost of up $10,000). If a resident is forced to cash in an asset to purchase such an item, the result is that this is deemed to be income, and the per diem is adjusted for the subsequent period based on the higher income.

The very small amount of residual income for the poorest residents means that any "extra charges" incurred could result in financial hardship, or decisions by residents to forego medically necessary but chargeable items and services. While there is concern that choices based on unaffordable user fees for social, recreational or personal hygiene services have the potential to negatively impact residents' quality of life, a greater concern arises if the choices affect medical treatments and supplies, creating potential negative health consequences and/or added cost to the healthcare system due to increased acute care admissions. One of the key objectives of this study is to examine the potential negative impacts of out-of-pocket charges on quality of life and health outcomes for residents, and on costs to the healthcare system.

3.12 Variability in Extra Charges

The Ministry of Health *Home and Community Care Policy Manual* governs the administration of finances for community and facility care, and defines operating procedures and required services for residential care facilities.[7] Chapter 8 of the policy manual defines what items and services must be provided without extra charge to residents of government-funded residential care facilities.

There are, however, different interpretations of the rules. Linda Thomas, Director for Contracted Residential Care and Assisted Living Facilities for Vancouver Coastal Health, used the term "huge" to describe the variability in resident charges for billable extras – those items and services not provided under the basic geared-to-income per diems (L. Thomas, personal communication, December 16, 2004). There is substantial inconsistency amongst facilities regarding the interpretation of items and services which are to be supplied free of charge to residents, and those which are considered billable extras (L. Rose, personal communication, December 21, 2004). Examples of inconsistent billing include room differentials (for semi-private, private, or other room amenities considered superior to standard accommodation in the given facility), over-the-counter medications, ostomy supplies, glucose monitoring strips, and even activity programs.[8]

---

[7] Chapter 6, Residential Care Services, defines such things as admission criteria, management of wait lists and transfers; Chapter 8 defines what items and services must be provided to residents without charge over and above the client per diem.

[8] Policy # 8.B., "Client Charges – Residential Care" of the BC Ministry of Health Services Home and Community Care Policy Manual sets out maximum allowable room differential rates as follows: single occupancy, $9.00/day; double occupancy, $6.00/day. The maximums are modified for rooms with no ensuite hand basin and toilet as follows: single occupancy, $4.50/day; double occupancy, $3.00/day.

The BC Ministry of Health Services lays out definitions of what constitutes care (items and services) to be provided without extra charge to facility residents. The policy defines care as:

> The delivery of services to assist the client in the activities of daily living: including accommodation; meals; therapeutic diets; nutritional supplements and meal replacements; skilled care and professional supervision; incontinence care; assistance with bathing, grooming, dressing an eating; management of the client's trust fund; and recreation activities (BC Ministry of Health Services, 2004, *HCC Policy Manual*, Policy 8B).

Services, programs or supplies falling under the above definition of care are to be provided to residents without extra charge. Policy 8.B of the *Home and Community Care Policy Manual* outlines the responsibilities of the facilities in some detail.

Figure 2: Service Provider Responsibility

Service Provider Responsibility

Residential care facilities are required to provide the following services to clients as a benefit:

- standard accommodation.
- skilled care with professional supervision consistent with the level of care required.
- development and maintenance of a care plan for each client.
- meals, including a therapeutic diet if prescribed by the client's physician and tube feeding.
- meal replacements and nutrition supplements as required by the client.
    - a meal replacement is a commercially formulated product that, by itself, can replace one or more daily meals. It does not include vitamin or mineral preparations.
    - a nutrition supplement is a food that supplements a diet inadequate in energy and essential nutrients. Nutrition supplements typically take the form of a drink, but may also be a pudding, bar or other form. They do not include vitamin or mineral preparations. Home made milkshakes or house brand supplements may be used except where the care plan or the client's physician specifically requires a named commercial brand for medical reasons.
- routine laundry service for the client's bed linens, towels, washcloths, and all articles of clothing that can be washed without special attention to the laundering process.
- hygiene supplies for the general use of all clients, such as soap, shampoo, toilet tissue, and special products required for use in century tubs.
- routine medical supplies such a sterile dressing supplies, bandages (elastic or adhesive), band-aids, syringes (reusable or disposable), catheters, disposable underpads for bed and chair use, equipment that is physically attached to the facility, and equipment that is for the general use of all residents in the facility.
- incontinence management as follows:
    - a toileting program, such as routine toileting, for incontinence control and, where necessary, a diapering service.
    - underpads, briefs and inserts: reusable or disposable.
    - catheters: indwelling, straight, catheterization tray, drainage tubing, drainage bag, irrigation set, irrigation solution, leg bag drainage set.
    - condom drainage sets.
    - disposable gloves: sterile or non-sterile.
- ongoing, planned physical, social and recreational activities, such as exercise programs, concerts, crafts, bingo.
- shared equipment, such as wheelchairs and walkers, for the short-term general use of all clients.
- any other service (such as drugs or added care) the facility has been funded to provide.
- extended care hospitals or units, and multi-level care funded facilities are required to provide the following additional services to clients as a benefit:
    - rehabilitation services; and
    - social work services

The same policy provides for some items which can be charged to the client, and specifies that these are to be provided at cost – that is, without administration fee or other mark-up.

Examples are given of items which can be charged to residents, but the policy indicates that the list is illustrative rather than exhaustive. The list of items is extensive. It includes: personal hygiene and grooming supplies; personal dry cleaning; personal telephone and cable television; personal newspapers and magazines; hearing aids and batteries; transportation; extra craft supplies and activities; as well as charges for preferred accommodation[9] (termed a room differential). Clients also pay for the cost and maintenance of personal equipment – examples in the policy include walkers, crutches, and wheelchairs for the client's exclusive use. The cost of these items can be quite substantial, and if affordability problems result in the client not being able to purchase the equipment, there may be negative implications for quality of life and health outcomes, and potentially added costs to the healthcare system.

3.13 Requirement to Accept First Available Bed

A requirement of BC's residential care admission criteria is that clients must accept the first available and appropriate bed. Because there are differences in out-of-pocket charges in different facilities, the amount residents will be charged for such items as over-the-counter medications, room differentials, and certain therapies is a matter of pure chance, depending upon where the first appropriate bed becomes available when the client is assessed as qualifying for residence. The client must generally occupy the bed within forty-eight hours of being advised of the availability of the bed; and must agree to pay all applicable costs of the particular facility which has a bed available. The current system allows for patients to receive different levels of insured service for identical per diems at government-funded long-term care facilities. The Ministry recognizes this as a serious equity issue (Thomas, Rose, Archibald, Helfrich interviews).

Residents are allowed to place themselves on waiting lists for transfer into preferred facilities within the health authority, and some residents move when beds become available in their facility of choice after initial placement in the first available bed.

---

[9] Room differentials cannot be charged to residents whose sole income in O.A.S/G.I.S. Maximum allowable room differential rates are $9.00 per day for single occupancy; $6.00 per day for double-occupancy. The above maximums are modified a follows for rooms with no ensuite hand basin and toilet: $4.50 per day for single occupancy and $3.00 per day for double occupancy. The facility must obtain health authority approval to charge room differentials for specific rooms.

3.14 HEU Study On Influence of Ownership Type

The 2002 HEU *Profits Distort Priorities* study found some evidence in a sample of twelve Vancouver-area facilities that for-profit facilities billed residents greater amounts for a larger number of items and services than not-for-profit facilities matched for similar characteristics and patient mix. The study also suggested further research to determine whether or not extra billing is on the rise in both ownership types due to increasing budget constraints since 2002.

Some findings from 1999 data gathered for *Substudy # 5* (Hollander et al., 2002) compared community and facility care in Victoria, British Columbia and Winnipeg, Manitoba. Selected data from Table 7-9 of the Substudy # 5 report presented below itemized mean annual costs for formal and informal care categories, including out-of-pocket expenses.

Table 5: Selected Mean Annual Costs for Facility Care for Clients with 120 Hours/Month or Less of Care Aid Time From Table 7-9, Substudy # 5

Location and Level of Care[10]	Continuing Care Costs[11]	Physician & Hospital Costs	Total Formal Care Costs[12]	Facility User Fees	Out-of-Pocket Expenses[13]	Informal Caregiver Time at Replacement Wage[14]	Maximum Costs to Client and/or Informal Caregiver[15]
1	2	3	4	5	6	7	8
Victoria							
Level A	**$33,805.20**	**$ 579.17**	**$34,384.37**	**$10,291.78**	**$1,499.18**	**$3,371.89**	**$15,162.85**
Level B	**$39,885.40**	**$ 256.67**	**$40,142.07**	**$11,000.58**	**$1,574.46**	**$4,247.70**	**$16,822.74**
Level C	**$45,923.23**	**$ 958.70**	**$46,881.93**	**$10,867.00**	**$1,722.69**	**$5,243.00**	**$17,832.69**
Level D	**$55,357.91**	**$ 379.23**	**$55,737.14**	**$11,427.59**	**$2,356.52**	**$8,216.52**	**$22,000.63**
Winnipeg							
Level B	**$45,169.74**	**$ 159.55**	**$45,329.29**	**$11,673.70**	**$ 308.57**	**$1,980.36**	**$13,962.63**
Level C	**$45,302.90**	**$ 255.41**	**$45,558.31**	**$13,406.55**	**$ 903.56**	**$2,745.45**	**$17,055.56**
Level D	**$40,727.51**	**$ 675.38**	**$41,402.89**	**$12,807.15**	**$1,068.70**	**$3,165.17**	**$17,041.02**
Level E	**$45,866.86**	**$ 880.00**	**$46,746.86**	**$13,324.14**	**$1,599.14**	**$2,214.38**	**$17,137.66**

Substudy # 5 found that clients and informal caregivers contributed about one-third of the care costs of facility clients in 1999, and that out-of-pocket costs ranged from a low of $308.57 per year for Level B Clients in Winnipeg facilities, to a high of $2,356.52 per year for Level D

[10] Column 1: Client functional abilities were assessed using the Functional autonomy Measurement System or SMAF. **Level A** represents "Somewhat Independent" clients with SMAF scores of 14.0 – 22.5; **Level B** represents "Slightly Independent" clients with SMAF scores of 23.0 – 35.0; **Level C** represents "Slightly Dependent" clients with SMAF scores of 35.5 – 45.5; **Level D** represents "Somewhat Dependent" clients with SMAF scores of 46.0 – 61.0; and **Level E** represents "Largely Dependent" clients with SMAF scores of 61.5 to 68.5.

[11] Column 2: Continuing Care Costs include facility user fees.

[12] Column 4: Total Formal Care Costs are the sum of Continuing Care Costs, Physician and Hospital Costs (Columns 2 and 3).

[13] Column 6: Out-of-Pocket Expenses are costs paid directly by the client and/or informal caregiver. Care-related costs itemized in expense diaries included: food for special diets; medical supplies; prescription and non-prescription drugs; herbs or other remedies; services of care providers not covered by Medicare, such as herbalists and naturopaths; transportation costs related to care; user fees, co-payments; and full cost (where applicable) for healthcare services such as physiotherapists; and other care-related expenditures.

[14] Column 7: Replacement wage was determined on a site-specific basis, using the wages of the particular facility for provision of the time/services supplied by the informal caregiver. They do not relate to the lost wages or opportunity costs actually attributed to the informal caregiver, which would depend on what income they could have earned working those hours in their own professions.

[15] Column 8: Maximum Costs to Client and/or Informal Caregiver is the sum of Facility User Fees, Out-of-Pocket Expenses and Informal Caregiver Time at Replacement Wage Columns (5, 6, & 7).

Clients in Victoria facilities. The out-of-pocket costs were characterized by researchers as fairly modest (Hollander et al. 2002 p. 60).[16]

Subsequent to *Substudy # 5*, PRAP criteria have resulted in much higher acuity levels amongst those admitted to long-term care in BC, and the care levels A, B, and C in their study findings have little relevance to the current long-term care population. Thus the figure of $2,356.52 for Victoria residents is best used for comparison purposes with current data.

Given that the poorest residents of BC's long-term care facilities receive total income from OAS/GIS of $1,032 per month as of January 2005, and that disposable income after payment of per diems is only $177.54; what *Substudy # 5* characterized as "fairly modest" out-of-pocket costs in 1999, would exceed the remaining income of residents by $18.84 per month. Since *Substudy # 5*, many items and services have been de-listed from insured services in BC, and the increased cost of many items and services (such as pharmaceuticals) has far surpassed the modest increases in OAS/GIS income levels attributed to CPI indexing.

Based on data from *Substudy # 5,* it is reasonable to hypothesize that out-of-pocket charges are unaffordable for low-income residents in BC's long-term care facilities. Evidence from the current study (caregiver surveys and family expense diaries) supports that hypothesis.

As well, *the extensive time and resources required to obtain useful data on out-of-pocket expenditures using this methodology was a significant finding related to the current study question..*[17]

Dr. Miller, one of the primary investigators, reported that their researchers did not code for-profit/not-for-profit information; so that study data cannot be used for comparisons of the two types of facilities.

---

[16] Affordability of these out-of-pocket costs for low-income residents will be discussed in the results section of this paper, with updates reflecting the current situation regarding chargeable items and services in 2005.

[17] Substudy # 5 methodology combined face-to-face interviews of patients, formal and informal caregivers, with the use of 3 diaries designed to document caregiving time and activities, and out-of-pocket expenditures. The methodology was extremely labour- and time-intensive, and required co-operation of health authorities, facility administrators and staff, residents, families, and other informal caregivers. Twenty-four staff were required to oversee and implement data collection by meeting with participants and remaining in telephone or other personal contact every two or three days.

3.14.1 Nine Related Studies Regarding Impacts of Increased Out-of-Pocket Costs to Patients

Nine other key studies summarized in Appendix B provide a sample of literature which documents the impacts of user fees or co-payments for medication and services on patient utilization rates and health outcomes. These results are highly relevant to the current study because one of the key objectives of this study is to examine potential impacts of out-of-pocket charges on quality of life and health outcomes for long-term care residents, the majority of whom are very low income. The correlation of patient out-of-pocket costs to usage of medically necessary items and services has implications for health outcomes and costs to the healthcare system as a whole.

While a number of these studies dealt with other age cohorts and were from other jurisdictions, the 1991 study by Soumerai et al. related to US seniors, and both Tamblyn studies included Canadian seniors in the study sample. I believe it is reasonable to generalize results on usage from the other studies as well, and to hypothesize that findings hold true for the frail elderly cohort residing in BC's long-term care facilities as they did in the Soumerai et al. and Tamblyn work. These studies all conclude that increased out-of-pocket cost to patients is inversely correlated with their use of the medication or service, and sometimes has unintended negative health impacts when patients limit or forego medically necessary medications or services.

Some of the findings were quite dramatic, not only in terms of increased suffering to patients, but also in terms of increased cost to the healthcare system. For instance, the 1994 Soumerai et al. study found that increasing out-of-pocket psychotropic medication costs to schizophrenic patients resulted in increased cost to the healthcare system which exceeded drug cost savings by a factor of seventeen. Increased suffering by affected patients is inferred.

3.14.2 Studies Regarding Out-of-Pocket Costs of Other Medically Necessary Items and Services

There is another large category of expenditures which is not captured in the above studies. This includes items and services such as optometry and prescription eyeglasses, audiology and hearing aids, dentistry, dentures and hip protectors, among other things. Below are selected studies related to hearing aids, dentures, dentistry, and hip protectors. Affordability of these items and services has serious implications for quality of life and health outcomes for long-term care residents. They are discussed in some detail here because these items and services are commonly required by long-term care residents to maintain quality of life and optimum health,

and, as well, policy makers require information on the costs and benefits of insuring these items and services if they are to make rational decisions for efficient delivery of long-term care services.

3.14.2.1 Studies Regarding Costs of Hearing Aids

At least one-third of the elderly have significant hearing impairment. A 1994 report by *The Canadian Task Force on Preventive Healthcare found that eighty-four percent of people tested in Canadian nursing homes had hearing impairmen.* (Patterson, 1994). A high percentage of cases of hearing loss are amenable to amplification. Hearing loss is very serious in the elderly, because it can impair physical and social function. Further, it is associated with cognitive deficits, mood disturbances and behavioural disorders.

> Hearing impairment is associated with diminished function in the elderly. For example, in a case series of older individuals screened in primary care practice, a 10 dB increase in hearing loss was associated with a 2.8 point increase in physical Sickness Impact Profile scores. Hearing impairment is associated with more rapid decline in cognitive function in people with Alzheimer's diseases. Even mild hearing loss is associated with memory failure (Patterson, p. 2).

According to the BC Association of Speech Language Pathologists and Audiologists (BCASLPA) website, full diagnostic hearing tests performed by an audiologist typically cost anywhere from $35.00 to $75.00. The cost is not covered by the Medical Services Plan of BC unless performed at a hospital or public health unit.

Hearing aids are quite costly, ranging in price from approximately $850 to $3,500 each. Appendix B provides the range of costs for individual hearing aids according to the 2003 BCASLPA fee guideline. In the majority of cases the hearing impaired require two hearing aids, so the cost per person ranges from $1,700 to $7,000. The life of a hearing aid is usually about 5 years, and often repairs are necessary which cost between $120 and $400 depending on the age of the device and the nature of the damage. There is no universal government assistance for the purchase or repair of hearing aids in BC, or for the purchase of batteries, although some specific categories of individuals such as Veterans or Registered Indians my be eligible for full or partial assistance and some extended health insurance plans partially or fully cover the cost

3.14.2.2 Studies Regarding Costs of Dental Care

A 2002 paper in the Journal of the Canadian Dental Association describes a BC study which points out that there are serious problems related to lack of provision of dental care in

long-term care facilities. The study took place between 1998 and 2000, and documents the dental health of 369 elderly dentate subjects residing in thirty-nine long-term care hospitals in the Vancouver area. A total of 310 (eighty-four percent) of the subjects lived in twenty-four intermediate care facilities, while the remaining fifty-nine (sixteen percent) lived in extended care facilities. Findings were that *a high percentage of residents had serious dental health problems for a variety of reasons* (Wyatt, 2002, p. 362)[18] One of Wyatt's disturbing conclusions targets barriers to receiving dental care, not the least of which is cost. The issue of dental health is therefore highly relevant to the current study regarding financial hardship experienced by residents of long-term care in BC. Wyatt's findings point out yet another adverse health effect which may result if residents cannot afford necessary preventive and treatment options. He concludes that:

> ...hospitalized elderly people experience barriers to receiving dental care, including cost, lack of perceived need for care, transportation problems and fear...Barriers to professional care must be removed and prevention strategies formulated to reduce the risk of oral disease, including caries (Wyatt, 2002, p. 362).

The study goes on to recommend early intervention, education of health professionals in identification of patients at risk, and implementation of preventive programs. Recommended caries prevention programs have not been implemented in BC's long-term care facilities, and residents without adequate financial resources may do without necessary treatment. Poor dental health can have very serious spill over impacts on quality of life and on health outcomes.[19] The dental health study is very relevant to my research, because the serious health impacts of bad dental health may cost the overall health system more than providing the needed care as an insured service. Further study of the cost of poor dental health in long-term care facilities would provide useful information to policy makers.

---

[18] Residents of LTC hospitals have inadequate daily oral hygiene, high sugar intake, high levels of caries bacteria and propensity for xerostomia, all of which result in moderately high plaque and extremely high risk of caries."

[19] Xerostomia, or dry mouth, is very common amongst long-term care residents. It has numerous causes, including being a common side-effect of many medications. Xerostomia can negatively affect dietary habits, nutritional status, speech, taste, and tolerance to dental prostheses. It also dramatically increases susceptibility to dental caries.

3.14.2.3 Studies Regarding Cost of Dentures

In a study for Statistics Canada, People Patterns Consulting projected that prescription and fitting of dentures would be the fastest growing Canadian expense item in the next fifteen years. Susan Poizner, in a special to the Toronto Sun, referred to the Statistics Canada study.

> Until 2016 – when the oldest of the baby boomers turn seventy – Statistics Canada says the cost of dentures will be the country's fastest growing household expense apart from shelter and taxes.

An article appearing in the May 2000 issue of the Ontario Dentist, indicated that approximately eight percent of Canadian seniors live in institutions. As previously noted, studies have documented that most institutionalized seniors have unmet dental needs. *Approximately fifty percent of institutionalized seniors wear dentures* (Goren and Baird, 2000, p.15). This is yet another extremely expensive, medically necessary item required by half of the residents of long-term care facilities.[20] If a resident's remaining income after payment of per diem charges does not allow for the purchase of proper dentures, serious adverse health could result.

It is not uncommon for residents' dentures to be lost, leaving them without the ability to speak or eat properly while awaiting a replacement prosthesis if they can afford to purchase a replacement. It is generally impossible to obtain insurance coverage for loss of dentures (Myer, 2005). Impaired ability to eat nutritious meals and to communicate have obvious negative health implications.

3.14.2.4 Studies Regarding Cost of Hip Protectors

In January 2004, the BC Office of the Provincial Health Officer produced a report entitled *Prevention of Falls and Injuries Among the Elderly*, which documented the enormous cost and growing incidence of falls among the elderly, including those in residential care. Statistics from the report highlight the prevalence of the problem of falls and hip fractures amongst this particularly susceptible cohort. The Provincial Health Officer terms the incidence

[20] The cost of a full set of dentures, comprised of both upper and lower arches, costs approximately $1300 if purchased from a Vancouver denturist. Two partial arches (where some natural teeth remain), actually cost more, because of the complex construction. Each partial costs approximately $850 so both arches would total $1700 (Anthony Chung, Denturist, telephone estimate, March 11, 2005). The charge is slightly higher if the dentures are purchased from a dentist. The BC Dental Association Fee Guide (which allows some variability in pricing, as the guide does not impose, but rather suggests price limits) lists the fee for each full arch denture as $540. Lab costs are added, and are approximately $375 per arch, for a total of $1830 for a full set of dentures, and somewhat more for two partials. (Vancouver Centre Dental Clinic phone estimate, March 11, 2005). John Myer, Registrar of the BC College of Denturists placed the cost as high as $4,000.00 (J. Myer, personal communication, March 11, 2005).

and cost of falls amongst the elderly a serious public health concern. The report concludes that risks and harm from falls can be reduced by various interventions, including exercise programs, clinical interventions, and the use of protective devices such as hip protectors. Many of the report's thirty-one recommendations regarding fall and injury prevention relate directly or indirectly to this current study of out-of-pocket costs for long-term care residents. The statistics regarding the incidence and cost of falls are sobering. It is estimated that there are on average 1.5 falls per year for every bed in long-term care (Office of the Provincial Health Officer, 2004, p.78). Figure 3 below contains some of the more relevant statistics in the report.

Figure 3: Selected Statistics from "Prevention of Falls and Injuries Among the Elderly: A Special Report from the Office of the BC Provincial Health Officer, January 2004

- Falls are the most common cause of injury for elderly people;
- Approximately 1 in 3 persons over age 65 is likely to fall at least once each year;
- Between 5 and 25 percent of those who fall experience a serious injury such as a fracture or sprain;
- In 2001, 20,000 seniors in BC were hospitalized because of a fall, and 771 people died directly or indirectly as a result of a fall;
- In 2001, about 3,100 BC seniors, two-thirds of whom were women, were hospitalized for a broken hip;
- Falls cause more than 90 percent of all hip fractures in the elderly and 20 percent of seniors who suffer a hip fracture die within a year;
- A single hip fracture adds $24,400 - $28,000 in direct costs to the healthcare system;
- **30 percent of hip fractures occur among 5 percent of seniors living in residential/institutional settings;** [emphasis added]
- Almost half of people who sustain a hip fracture never recover fully;
- Falls among seniors can cause long-term disability, chronic pain, and lingering fear of falling again.
- Injuries from falls account for 85 percent of all injuries to the elderly

Frail elders in long-term care facilities are extremely vulnerable to falls and hip fractures because they often suffer from chronic illnesses, impaired cognitive function, inactivity, use of high-risk medications, muscle weakness, impaired vision, poor balance and so forth. Many medications to combat dementia impair balance, gait, judgment and reaction time.

The report also cites "reduced caregiver/patient ratios" as a predisposing factor to falls. Lack of adequate staffing for supervision of transfers, and inadequate services of physiotherapists were also cited as a risk factors.

> Maintaining muscle strength and physical abilities is difficult in institutional settings lacking the resources for on-site physiotherapists and exercise programmers" (Office of the Provincial Health Officer, 2004. p. 48).

The report cited the importance of maintaining and enhancing bone density with calcium and vitamin D, as well as bisphosphonate bone-enhancing drugs to reduce the incidence and severity of osteoporosis. Subsequent sections of this paper discuss out-of-pocket costs for hip protectors, vitamin supplements and other medications, some of which are required to maximize the protective effects of prescription osteoporosis medications.

Use of hip protectors to cushion the hip from the impact of a fall was a recurring theme throughout the report which emphasized that free provision of hip protectors increases their use among the elderly.

> The report cites a 2003 BC research study which found with the low unit cost of $150, hip protectors could save money, prolong life, and improve quality of life for long-term care residents (Office of the Provincial Health Officer, 2004. p. 64).

A controlled research trial on the benefit/cost for provision of hip protectors and other bone-enhancing strategies at no cost to long-term care residents would provide extremely useful information to policy makers.

4 Results from Case Study Expense Diaries

The Hollander et al. (2002) study discussed in the literature review led to my methodology of employing questionnaires and two-week expense diaries completed by family members. The four diaries and questionnaires serve as individual case studies which provide in-depth information regarding out-of-pocket costs for four individuals and their families. The case studies provide details of the impacts of out-of-pocket costs on residents and their families.

Two week diary expenses included regular monthly facility charges for basic room, board and care, and additional funds billed to the resident or family by the facility, deducted from the resident's comfort fund, or expended by family members to provide additional items or services to the resident. A copy of the expense diary and questionnaire is provided in Appendix P. Individual results of case studies one to four are contained in Appendices H, I, J, and K.

4.1 Physical and Cognitive Limitations of Residents

Information contained in Table 6 regarding the physical, cognitive and health-related conditions of residents illustrates the acuity of care required by residents, which, in turn, relates to the number and type of items and services which are likely to be required to ensure optimal quality of life and optimal health outcomes. The high care needs, multiple health problems, and cognitive impairment of the case study residents is typical of the larger population of long-term care residents. Under the stricter eligibility requirements imposed by the BC government's 2002 Provincial Residential Access Policy, all clients admitted to facility have high and complex care needs.

Table 6: Physical and Cognitive Limitations and Diagnoses of Residents

Case Study #	Physical Limitations	Cognitive Limitations	Chronic Conditions or Diagnoses
1	Mobility, hearing, vision, muscle control, soft voice, communication difficulties, balance	Dementia	Parkinson's Disease, Thyroid, Dementia
2	Left-side mobility problems (result of stroke), wheelchair full-time. Must use lift for transfer to bed and toilet. Some swallowing difficulty.	Some short-term memory loss. Knows family but cannot follow calendar for day and date	Osteoarthritis; heart pacemaker; urine incontinence; paper-thin skin
3	Cannot walk or transfer. Cannot feed or dress self. Hearing loss on right side.	Has lost language. Very good comprehension but cannot verbally communicate. Remembers the past well and understands what is happening around him. Some dementia.	Incontinent of bladder and bowel; arthritis in knees and hands
4	In wheelchair full-time.	Dementia	Dementia

4.2 Selected Family and Resident Demographic, Per Diem and Income Information

Table 7 summarizes demographic and cost information from the four case studies. It illustrates the age and work status of the family caregiver, the family member's relationship to the resident and whether or not there are other caregivers assisting; the frequency of visits; age and gender of resident; length of residence in a long-term care facility; the base and room differential charges for accommodation , meals and care; and the approximate gross income of the residents.

Table 7: Matrix of Selected Demographic Information from Diary Keepers

Case Study #	Age of Family Member	Work Status of Family Member	Sole Caregiver or one of Several Caregivers	Relationship of Family Member to Resident	Distance from Family Residence to Facility	Frequency of Visits	Resident Age	Resident Gender	Length of Residence in Long-Term Care	Per Diem and Monthly Rate	Room Differential If Applicable	Approximate Gross Income of Resident
#1	< 65	Retired	sole	daughter	3 kms	Daily	88	female	29 months	$66.30 = $2,027/mo.	none: in 4-bed room	$52,000
#2	< 65	Retired	one of a few	daughter	3.5 kms	3-4 times per week	92	female	30 months	$28.10 = $855/mo.	$7.50 = $233/mo. semi-private	$15,577
#3	< 65	Retired	one of a few	daughter	15 kms	3-4 times per week	88	male	48 months	$63.91 = $1,944/mo.	none	$40,000
#4	> 65	Retired	sole	husband	5.5 kms	twice daily	77	female	16 months	$32.85 = $999/mo.	$7.50 = $233/mo. semi-private	$18,000

4.3 Case Study Demographics Compared to the Target Cohort

Although the data in Table 7 from the individual case studies is not random, many demographics of this small sample are typical of the larger population. Similarities and differences are discussed below.

4.3.1 Gender, Age and Length of Residence in Facility

For example, within the general population more females than males are "informal caregivers", and females outnumber males in long-term care facilities. Resident ages over seventy-five in the case studies are also typical of the larger population. The length of stay of case study residents is, however, significantly longer than that reported to be typical by managers at Vancouver Coastal Health, who indicated that residents now generally enter facilities very late in their lives. The average stay prior to death in VCH facilities is currently only eighteen months.

4.3.2 Resident Incomes, Per Diems and Room Differential Charges

Case study resident incomes, and therefore per diem rates, are not representative of the proportion of the general population of facility residents at the lowest income levels. Amongst the four case study residents only one is in the lowest income range and paying the current minimum per diem. Within the general population, seventy-two percent fall into the lowest income category and pay the minimum rate.

It is noteworthy that the two lowest income case study residents pay room-differential charges of $233/month for semi-private rooms, because this is not typical of the larger cohort. There is a limit set by the Ministry of Health Services on the percentage of rooms in any facility (fifteen percent) which can be designated as superior accommodation and subject to room differential charges.

As well, there is a prohibition against charging room differentials to residents whose sole source of income is OAS/GIS; so these poorest residents generally cannot request or reside in superior accommodation subject to room differential charges. Gross resident income of $15,577 in case study # 2 less combined per diem and room differential leaves only $210 per month, which would translate into an even lower amount if net income (which is the appropriate measure) were used for the calculation. Similarly, gross resident income of $18,000 in case study # 4 less combined per diem and room differential leaves only $268 per month, which would again be less if calculated based on the appropriate measure, net income. As of January 2005, remaining income for the lowest income residents in facilities is under $180.00 per month after payment of per diems.

4.3.3 Chronic Conditions, Physical and Cognitive Limitations

As previously noted, the high number and great variety of chronic conditions, physical, and cognitive limitations of case study residents summarized in Table 6 fits the profile of the larger population of facility residents since the introduction of the 2002 Provincial Residential Access Policy (PRAP), which has resulted in eligibility for residential care being restricted to those with very high and complex care needs. All four case study residents have a degree of cognitive impairment, ranging from moderate to severe, which is also typical of the large population of facility residents.

This information is important, because the high needs of residents translate into potentially significant out-of-pocket costs for medically-necessary services (e.g. physiotherapy,

podiatry, chiropractic, etc.), items (e.g. special dressings, glucose monitoring strips, over-the-counter medications, etc.) and equipment (e.g. specialized wheelchairs, cushions, hip protectors, etc.) needed for resident safety, and to achieve optimum quality of life and health outcomes.

4.4 Capturing Extra (Out-of-Pocket) Costs Incurred by Case Study Residents/Family Members

Each of the case study family members completed a two-week expense diary itemizing out-of-pocket costs for items and services provided over-and-above those covered in facility per diem and room differential charges. Also included were out-of-pocket transportation costs to the family member (including parking charges and using a mileage rate of $0.45/km) for visits, errands, transporting the resident, and so forth.

Because the two-week expense diary data collection tool has a high probability of not capturing expenses which are representative of an "average" two week period, several additional questions were answered by participants. Two weeks is too short a period to capture even some regular monthly purchases; and likely misses bulk periodic expenditures. The diaries almost certainly miss large capital expenditures which are infrequently incurred (such as wheelchair purchases, hip protectors, special mattresses, specialized clothing, etc.), but need to be accounted for by some method of apportioned expense for the period. Other periodic large expenditures, such as dentistry, optometry, and so forth are likely to have been missed and need to be accounted for as well. Therefore several additional questions attempted to capture this data. In three of the four case studies, the two-week snapshot under-represented expenditures in an average two-week period, largely for the reasons cited above, but also due to bad weather and roads, and the timing of the diary period coinciding with the Christmas and New Year holidays.

Respondents were asked to mark the most appropriate answers to six questions intended to fill in information gaps created by limitations of the two-week diary methodology. These questions were intended to capture the following information:

- Do the types and amounts of expenditures itemized over the two-week diary period capture representative expenditures over an average two-week period, or did they under- or over-represent average expenditures?
- How often are items/services which would be a health benefit to the resident not purchased or accessed due to cost?

- Do out-of-pocket costs of residential care impose financial hardship on the resident or family?
- What is the frequency and cost of large capital expenditures, such as the purchase of a special mattress or the purchase or repair of a specialized wheelchair?
- What are the types and costs of any additional services purchased over-and-above the standard services provide by the facility?
- Are there general observations, experiences, or comments participants want to share regarding out-of-pocket expenditures by the residents or families?

Case studies are summarized individually in Appendices H, I, J, and K. Comments of respondents included in the individual summaries were transcribed verbatim from completed questionnaires.

4.5 Analysis of Case Study Expense Diaries and Questionnaires

Out-of-pocket costs documented by the four families, combined with basic per diems and room differentials exceed the residents' incomes in three of the four cases. The two case studies representing couples with one member in a residential care facility and one at home illustrate the common problem of having the additional expense of maintaining a residence, and perhaps financing home care for the partner still living in the family home.

The range and cost of extra items and services documented in the family diaries and questionnaires raises the question of what items and services cannot be purchased by other residents with low incomes or insufficient family support. The enormous cost of uninsured items like specialized wheelchairs, special mattresses and cushions, creates cause for concern because of the hardship and adverse consequences which can result if they can't be purchased.

The respondents involved in the four case studies are all family members who contribute considerable time and money to the care of the resident. It is not always the case that residents have family resources to draw upon, either in the form of assets or other family members' contribution to expenses. This is cause for additional research into the implications of unaffordable extra billing. The literature documents impacts such as poor dental health, poor nutrition, increased fall and fracture risk, isolation and cognitive deterioration, and increased risk of pulmonary embolism and pneumonia.

Residents included in the four case studies resemble other residents in terms of their physical and cognitive disabilities, but aren't necessarily representative of the larger resident cohort in terms of income or family support. Case study residents have sufficient income and/or access to family assistance in the form of time and/or money to ensure that needed items and services can be purchased. Since over seventy percent of residents are known to be very low income, and since new access criteria prioritize those with lacking availability of family caregivers and access to family support, it is fair to hypothesize that a large number of residents cannot afford out-of-pocket expenditures to access necessary items and services. Caregiver survey responses document that affordability problems create hardship for some residents.

5 Results from Facility Caregiver Telephone Surveys

This section describes telephone survey responses from the Caregivers at the eight facilities selected for the study. The survey questions are found in Appendix G. Questions were designed to elicit information about the types of items and services billed to residents at each facility, changes in billing practices since 2002, differences in billing practices between for-profit and not-for-profit facilities, and whether or not there is evidence of hardship to residents attributed to affordability problems. Caregivers confirm that both for-profit and not-for-profit facilities charge residents for a wide range of items and services, and that these charges are unaffordable and create hardship for some residents.

Results from a prior HEU long-term care study suggested that for-profit facilities charged for a greater range of items and services than not-for-profit facilities. One of the reasons for this study was to provide a comparison of current results to those from the HEU work. Caregiver responses in the current study did not, however, provide conclusive evidence regarding differences in billing practices between for-profit and not-for-profit facilities. The methodology section of the paper explains why the results of the current study cannot be reliably compared to the prior HEU results. Further research is required before any meaningful inference can be made regarding current differences in insured services between the two facility ownership types.

5.1 Interpretation of Itemized Caregiver Response Scores

Appendix L contains a table detailing the caregiver telephone survey responses to the question of extra billing in each of the eight facilities. Facilities were scored based on the number of items from the list in column six of the table provided to residents without charge. The score is derived by multiplying the number of items by a factor of zero, one, or two based on the level of coverage provided. If no coverage is provided (0 = no coverage; resident pays full price) the factor is zero (0 = no coverage; resident pays full price); if partial coverage is provided, the factor is one (1 = partial coverage; some residents pay, or all residents pay some percentage of the price based on a variety of circumstances); and if full coverage is provided the factor is two (2 = full coverage; no residents pay).

It is important to recall from the methodology section that there was no attempt to weight the survey items or services based on financial cost, or potential health or budgetary impacts. Analysis of caregiver responses is difficult without considering the potential financial and health impacts of the extra charges.

Aggregate facility scores calculated for each expenditure category by ownership type and for the entire cohort (calculations always utilized number or percent relative to valid answers received – excluding "don't know" answers) indicate that for many categories, differences in insured coverage between for-profit and not-for-profit ownership types were not significant.

5.1.1 Calculation Aggregate Scores for Insured Items

The aggregate facility scores shown in Table 8 below, indicate the prevalence of extra-billing in the sample facilities for twenty item and service categories. Numerical and percentage scores are based on valid responses only (eliminating "don't know" answers). Therefore maximum possible scores were derived by multiplying the maximum score per facility by the number of valid responses for each facility type and for all facilities.

Table 8: Aggregate Scores for 20 Categories of Insured Items/Services

Category & Maximum Score per Facility	Items Included in Category N and Description	Valid for-Profit Responses N	For-Profit Actual Score/Maximum Possible Score N/N (%)	Valid Not-for-Profit Responses N	Not-for-Profit Actual Score/Maximum Possible Score N/N (%)	Max. Possible Score from Valid Answers. All Facilities N	Actual Aggregate Score. All Facilities N (% Maximum Possible from Valid Answers))
Fruit laxative max score = 2	**1**	**4**	**8/8 (100%)**	**4**	**6/8 (75%)**	**16**	**14 (87.5%)**
Bowel care max score = 6	**3 OTC laxatives, enemas, suppositories**	**3**	**10/18 (55.6%)**	**3**	**4/18 (22.2%)**	**36**	**14 (38.9%)**
Wound care max score = 10	**5**	**4**	**18/40 (45%)**	**2**	**10/20 (50%)**	**60**	**30 (62.5%)**
Hip protectors max score = 2	**2**	**4**	**0/8 (0%)**	**3**	**0/6 (0%)**	**14**	**0 (0 %)**
OTC Medications max score = 10	**5 Imodium, Tylenol, Gravol, calcium, iron supplement**	**3**	**11/30 (36.7%)**	**4**	**3/40 (7.5%)**	**70**	**14 (20%)**
Oxygen max score = 2	**1**	**4**	**5/8 (62.5%)**	**4**	**4/8 (50%)**	**16**	**9 (56.3%)**
Ambulance transport max score = 2	**1**	**4**	**0/8 (0%)**	**4**	**0/8 (0%)**	**16**	**0 (0%)**
Other transport max score = 4	**2 taxi transport & other transport**	**4**	**0/16 (0%)**	**4**	**0/16 (0%)**	**32**	**0 (0%)**
Rehydration therapy max score = 4	**2 hypodermoclysis tubing and fluids**	**4**	**12/16 (75%)**	**1**	**4/4 (100%)**	**20**	**16 (80%)**
Glucose monitoring strips max score = 2	**1**	**4**	**6/8 (75%)**	**4**	**3/8 (37.5%)**	**16**	**9 (56.3%)**
Skin care max score = 8	**4 special mattresses, air mattresses, egg crate mattresses, roho cushions**	**4**	**8/32 (25%)**	**3**	**11/24 (45.8%)**	**56**	**19 (34%)**

Category & Maximum Score per Facility	Items Included in Category N and Description	Valid for-Profit Responses N	For-Profit Actual Score/Maximum Possible Score N/N (%)	Valid Not-for-Profit Responses N	Not-for-Profit Actual Score/Maximum Possible Score N/N (%)	Max. Possible Score from Valid Answers. All Facilities N	Actual Aggregate Score. All Facilities N (% Maximum Possible from Valid Answers))
Podiatry services max score = 2	**1**	**4**	**0/8 (0%)**	**4**	**0/8 (0%)**	**16**	**0 (0%)**
Mobility aids max score = 8	**4 wheelchairs, walkers, crutches, canes**	**4**	**0/32 (0%)**	**4**	**0/32 (0%)**	**64**	**0 (0%)**
Transfer aids max score = 6	**3 floor to ceiling bar, bedside assist bar, raised toilet seat**	**3**	**10/18 (55.6%)**	**3**	**12/18 (66.7%)**	**36**	**6 (16.7%)**
Bed alarm max score = 2	**1**	**4**	**6/8 (75%)**	**3**	**2/6 (33.3%)**	**14**	**8 (57.1%)**
Incontinence management max score = 14	**7 barrier cream, diapers, incontinence pads, condom drainage bags, urinary catheters, portable urinals, commodes**	**3**	**28/42 (66.7%)**	**3**	**37/42 (88.1%)**	**84**	**75 (89.3%)**
Nutritional supplements max score = 2	**1**	**4**	**6/8 (75%)**	**4**	**6/8 (75%)**	**16**	**12 (75%)**
Recreation max score = 4	**2 outings and within-facility activities**	**4**	**7/16 (43.8%)**	**4**	**10/16 (62.5%)**	**32**	**17 (53.1%)**
Companion Services max score = 4	**2 paid companions & escort services to doctors' offices**	**4**	**0/16 (0%)**	**4**	**2/16 (12.5%)**	**32**	**2 (6.3%)**
Extra baths max score = 2		**4**	**2/8 (25%)**	**4**	**7/8 (87.5%)**	**16**	**11 (68.8%)**

The three highest categories of coverage were 89.3 percent for incontinence management, 87.5 percent for fruit laxatives, and 80 percent for rehydration therapy. At the extreme opposite end of the coverage spectrum, there was no coverage at all for hip protectors, ambulance, taxi or other transport, podiatry services, or mobility aids (which can be extremely expensive, as itemized in Appendix F).

Although aggregate percentage scores in the high eighties may seem like respectable percentages, without a formula for weighting the cost of the item/service, or its potential health and budgetary impact, it is difficult to judge whether or not this is a satisfactory percentage of coverage. Given the critical importance of rehydration therapy, for instance, a score of eighty percent may be considered unacceptably low. Similarly, scores of less than one-hundred percent might be cause for concern in such critical categories as oxygen, bowel care, skin care, wound care, and so on.

Further study would be required to apply this in-depth analysis to every item and service on the list in order to determine the policy implications of mandating provision of specific items/services as a potential policy instrument.

5.1.2 Responses Showing Identical Coverage Between Ownership Types

Based on twenty categories of items and services in the table, there were no differences in *aggregate* scores for coverage between for-profit and not-for-profit facilities in six categories: hip protectors, ambulance transport, other transport, podiatry services, mobility aids, and nutritional supplements. For hip protector, ambulance and other transport, podiatry, and mobility aids categories there was no coverage (resident paying full charge) in any of the eight facilities; and in the category of nutritional supplements three out of four of each facility type provided full coverage (no extra charge to resident).

5.1.3 Interpretation of Remaining Itemized Responses

Appendix M details the survey responses of caregivers to the question of whether or not insured coverage has changed for each expenditure category since 2002. The question regarding changes since 2002 was posed to determine whether responsibility to pay for additional items and services had increased as a revenue generating mechanism in response to budget constraints. The methodology section of the paper provides an explanation of difficulties in interpretation of survey questions regarding changes in billing practice. The methodology section points out difficulties analyzing differences in insured coverage by ownership type from survey responses,

and the added caution that results detailed in Appendices L and M are not generalizable. In particular, more research is required before conclusions can be reached regarding billing differences between for-profit and not-for-profit facilities.

5.2 Free Response Caregiver Comments

The inclusion of free-response comments for each category provided particularly useful information in the form of specific examples of the positive correlation between hardship and adverse health outcomes and level of out-of-pocket costs to residents.

It is clear from the literature review that out-of-pocket costs are negatively correlated with access and usage. Caregiver responses to the survey questions provide evidence that many items and services are charged to residents of long-term care facilities, and key informant interviews confirmed that a range of items and services are charged to residents, with great variability amongst facilities and little access to information regarding amounts charged. Case study expense diaries and questionnaires also document substantial out-of-pocket costs to residents and their families. Therefore the caregiver answers to questions related to resident hardship were particularly helpful to meet the study objective of identifying impacts of out-of-pocket charges on quality of life and health outcomes for residents.

5.2.1 Needs Fund Provides Evidence of Hardship

There were numerous examples of resident hardship provided by free responses to the caregiver survey. In some instances caregivers reported that minor charges (such as transport in facility-owned vans or in-house recreation fees) can be waived *where hardship is a factor*. For other purchases, such as specific prescription medications, complex wound dressings, hip protectors, special mattresses, cushions or custom wheelchairs, caregivers report that if the cost is too high the items are simply not purchased.

Staff at one facility established a "needs fund" four years ago to assist residents to purchase needed but unaffordable items and services. The fact that staff established the needs fund is evidence that financial hardship exists amongst facility residents. One of the main sources of revenue for the aforementioned needs fund is a 50/50 draw which is held every pay day. Over seventy participating staff contribute $2.00 each pay period (bi-weekly) through a payroll deduction plan. A draw is held, and the winner keeps half of the funds, with the balance going into the needs fund. Facility fund-raisers and donations from families of deceased residents also contribute to the fund. When a resident cannot afford a necessary item or service, the registered

nurse makes application to the fund, and if sufficient money is available, the cost of the purchase can be covered. Money in the needs fund is insufficient to pay for more expensive items such as hip protectors, which are high cost items needed by many residents. The caregiver's comment was that purchasing needed hip protectors would "wipe out the fund." In terms of frequency of use, the caregiver's comment was, *"The needs fund is accessed a lot."*

5.2.2 Other Evidence of Hardship

There were numerous responses regarding hardship resulting from unaffordability of hip protectors and wheelchairs. Due to issues of custom fit, infection control, and so forth it is usually not advisable for residents to borrow, rent, or share these items. Table 8 below contains selected free response comments from the telephone survey of caregivers. Respondents from six facilities commented on the hardships around the high cost of wheelchair purchases, and five commented on the hardships around the unaffordability of hip protectors. Caregivers also provided examples of affordability problems with some over-the-counter and specific prescription medications, ostomy supplies, and complex wound dressings which are not covered under Pharmacare Plan B which applies to long-term care residents. Caregivers cited the cost of companions and escort services as a growing concern based on higher acuity levels of residents, and staff shortages attributable to higher needs patients and facility budget constraints.

Table 9: Caregiver Free Responses Regarding Financial Hardship

Item or Service	Comment
Hip Protectors	Family members are struggling to pay the $125 for the hip protectors now, but the new ones will be more expensive. Hip protectors are not covered by the needs committee yet. It would wipe out the fund.
	Residents are assessed for fall risk upon admission or if they begin to experience falls. Families are advised that the hip protectors provide significant protection...Need at lest two pairs (must be custom measured...) This may create a financial hardship for some.
	On admission the residents are assessed for fall risk, and when the families hear the cost of hip protectors, they decline them. Not many residents use them, but they should.
	Know of a wife who was hesitant to buy hip protectors as they are so expensive. Used one that was given to the facility from a family of a deceased resident.
Hip Protectors & Roho Cushions	Could affect care – especially Roho cushions which cost $600 each. Some people won't pay for them, but most get them through their family. Note: If they could share things they would, but some things can't be shared, e.g. hip protectors. Infection control issues prevent sharing.
Mattresses and Wheelchairs	In the past; when people died; mattresses; wheelchairs; etc. were donated. now things are thrown out and everything is either rented or purchased rather than loaned to residents.
Wheelchairs	If can't afford; facility has standard ones; but is an insurance concern so they don't advertise that this is available. If needed for special posture issues, the family is asked to buy special chair.
	If physiotherapist says patient needs something and they can't afford to pay for it, thy don't get it. We may have some wheelchairs that another resident left, but they are not always the best fit for the resident.
	If residents can't afford something, wheelchairs for example, they will go to community groups, or try to get a loaner. Loaners may not be optimal for the patient.
	Quite a few family members are hesitant to incur the cost of a custom wheelchair. Physiotherapist measures residents for the fit of the chair needed before ordering. They cost a few thousand dollars. The facility will provide a temporary chair, and the family will ask to use it even if it is not correct for full-time use by the resident. The facility has some donated wheelchairs.
	Wheelchairs cost too much for some families, so they go to a cheaper, less-appropriate chair for the resident.
Medications	Over-the-counter laxatives are not covered and the residents are not able to afford. They try other means; but not helpful;
	Sometimes the pharmacy will phone to say a drug is expensive and they can provide a cheaper drug or that they need special approval to supply the drug. The drug can be changed or the family has to pay for it. Sometimes the resident has sold their house when they come into the facility. The children help take care of the costs until the money runs out.
	Example of a situation. Anti-psychotic medication needed by resident and drug was not covered by Pharmacare. And the resident and family did not want to pay for it, but the staff felt that it was need if they were going to be able to provide care. The case was referred to the needs committee for funding.
	Sometimes the residents don't have funds. A resident needed measalt packing, and had to buy them. The measalt was stopped because the resident could not afford. They used another type of dressing.
	Residents experience hardship. Checked with RN and she said residents are changed to a generic drug and it may not be as effective as the drug originally ordered.
	Yes, residents experience hardship. The pharmacy will ask to phone the family to give the costs of the drug ordered. The family may decline to pay if they wonder if they get the benefit with the supplemented drug.
Ostomy Supplies	Ostomy supplies are expensive and so we look for funding for the residents.
Companion and Escort Services	Paid companion not covered unless patient is uncontrollable. Can apply for some government money to pay for companion in this situation, but it is not always enough.
	The cost of a companion or escort service has an impact. If can't afford, medical appointments could be cancelled. If urgent, long-term care is approached to cover costs, but they rarely do. The acuity of residents is increasing and there is more need for extra help and some can't afford the extra help. Once volunteers were used as escort services, but there is a change in policy as it is not appropriate to use them as they are untrained.
General	Yes, there is hardship. If the family thinks something is too expensive, they don't buy it. We can rent out some items, but if they can't afford, they don't get it.

The specific examples of hardship provided by caregivers in their free-response comments confirm the common findings in the literature that out-of-pocket charges result in reduced access and usage. Adverse consequences resulted in several examples. Resident discomfort aside, there may also be unintended costs to the healthcare system which outweigh cost savings. Recall the discussion in earlier in the paper concerning increased risk of hip fractures and the attendant cost to the healthcare system.

6 Results from Key Informant Interviews

I interviewed senior mangers from the provincial Ministry of Health, the Vancouver Coastal Health Authority, and the BC Care Association because of their particular knowledge and role in the delivery of long-term care in BC. The interviews were open-ended, because the experts could discuss with me research questions I might not have known to explore, as well as answering my basic questions regarding the current delivery, reporting and accountability mechanisms. For example, updated policies from the provincial *Home and Community Care Policy Manual* (which defines regulations for chargeable items and services in government-funded long-term care facilities) are not available on the internet without a government password. Interviews with key informants led me to current information on policies.

I conducted interviews with Karen Archibald, Manager of Information and Policy for the Home and Community Care Division of the Ministry of Health Services; Linda Thomas, Director of Residential Care and Assisted Living Facilities for Vancouver Coastal Health (BCH); Linda Rose, Director for VCH Directly-Operated Long-Term Care Facilities; Nancy Rigg, Executive Director of the Community Care Network from the Regional Office of VCH; and Ed Helfrich, Executive Director of the BC Care Association. Main points of each interview are summarized in Appendix N, and common themes are highlighted in this section of the paper.

6.1 Common Themes from Key Informant Interviews

Several common themes emerged from the key informant interviews. They relate to operational and legislative matters; historical and future management of out-of-pocket costs to residents.

6.1.1 Need for Accurate Information On Extra Billing

The first common theme amongst the interviewees was the need for accurate information regarding extra charges in long-term care facilities. There is currently no reporting or accountability requirement for extra charges to residents. Billings against resident "comfort

funds" or trust accounts are only examined if there has been a complaint leading to an audit. The BC Ministry of Health Services is aware of the problem, and has empowered a working group called the "Optional Goods and Services Working Group" to study the problem and make recommendations back to the ministry.

Ed Helfrich, Executive Director of the BC Care Association, who sits on the committee made up of health authority and provider representatives, says that it has been difficult obtaining information from facilities, which can be hesitant to provide information regarding billings from comfort funds or trust accounts. He advised me, in fact, to request information from the public trustee which he felt would be easier to obtain than information from facilities.[21]

Linda Thomas, Director of Contracted Residential Care and Assisted Living Facilities for Vancouver Coastal Health, confirms that the Ministry of Health Services has initiated a province-wide process to examine chargeable items and services, and lauds the initiative because she does not feel that this is just a Vancouver Coastal Health problem or that Vancouver Coastal Health should take a lead role. She indicated that Vancouver Coastal Health is, therefore, hesitant to gather information until the province determines what should be done.

The Optional Goods and Services Working Group has been examining the problem for over 8 months, and has drafted a revenue generation policy outlining what must be included in facility per diems, but this information is not public as of this writing. The group's work has not addressed the pharmacy issue, which Ms. Archibald describes as "huge and difficult," and which she indicates could require an additional three years of study. The draft revenue policy deals with supplies and equipment, as well as room differentials, which several interviewees, including Archibald, describe as a big concern on two fronts. These are outlined below.

6.1.2 Two Areas of Concern Regarding Room Differential Charges

One concern regarding variability in room differentials, is the issue of fairness to residents. Differentials for semi-private and private rooms, or rooms deemed to be "preferred" accommodation compared to standard rooms in a given facility range from $3.00 per day to $9.00 per day in non-hospital designated facilities. In other words, the additional charge may be as high as $274.00 per month.

There is no upper limit for charges in hospital-designated facilities, which have been known to charge room differentials as high as $25.00 per day, or $760.00 per month. Because of

[21] My request to the Public Trustee was turned down.

changes in new building requirements to require standards appropriate for "complex care" (in line with stricter eligibility criteria for admission into residential care), new facilities only provide single rooms, and therefore no room differentials are charged in those facilities.

This leads to the anomaly where there are newer, nicer rooms in some facilities without room differentials, compared to less-desirable rooms in older facilities for which differentials still apply. Recall that residents must take the first available room offered to them and occupy the bed within forty-eight hours. Although subsequent transfers are allowed and are not uncommon, only forty percent of residents are initially placed in their preferred facilities. It is acknowledged that the choice of where a resident is placed, due to chance bed availability, results in different charges for similar items and services.

The second concern raised by interviewees is the potential loss of substantial revenue to long-term care facilities currently operating under the *Hospital Act*, should they be transferred to the jurisdiction of the new *Community Care and Assisted Living Act* under section 12 of that Act. This is one of the areas (along with potential loss of preferential GST treatment for *Hospital Act* facilities) which is under study. This is one of several reasons why Linda Rose indicted that the initiative to consolidate all long-term care facilities under the *Community Care and Assisted Living Act* may not be completed for some time to come.

6.1.3 Variability in Application of Other Extra Charges

All interviewees acknowledge that there is currently great variability amongst facilities regarding extra charges beyond those associated with room differentials. This is due in part to historical reasons related to which legislation governs each individual facility, as discussed above, but also in large part to differences in interpretation of the *Home and Community Care Policy Manual*. There is no official reporting or accountability requirement for extra charges to residents; so neither the range nor cost of items and services paid for out-of-pocket by facility residents is known for certain. Neither, by extension, are the impacts of extra billing known, in terms of resident quality of life or health outcomes.

Despite the fact that there is no official reporting requirement or accountability mechanism regarding extra billing, all key informants acknowledged that there is known variability in charges for ostomy supplies, diabetic strips, and recreational activities, as well as for over-the-counter medications. The list of items which must be provided without extra charge to residents under the current application of the *Home and Community Care Policy Manual*

includes ostomy supplies, diabetic strips and basic recreational activities; yet it is known that many facilities extra bill for these items and services.

6.1.4 Reviewing the Impacts of De-Listed Items and Services

A fourth theme was the need to review the types of items and services provided in long-term care facilities based on efficiency criteria. In particular, the de-listing of some medications from the provincial formulary and reductions in coverage for services such as physiotherapy, occupational therapy, podiatry, and social work were mentioned as areas for reconsideration. In light of much stricter facility eligibility requirements and higher acuity levels of patients since the implementation of PRAP, some interviewees indicted that there is a need for policy analysts to assess the impact on residents and the overall healthcare budget of co-payment for these items and services. Karen Archibald reports that there is a possibility that such a review would lead to re-insuring some of the services for which coverage was stopped in 2002. Specific services under discussion include physiotherapy, occupational therapy, podiatry, chiropractic, massage therapy and social work.

7 Results from Retail Price Gathering

I priced numerous medically-necessary items and services which are commonly required by long-term care residents in order to document a range of prices which could be paired with other study methods to assist with my analysis of out-of-pocket costs. For example, the literature informs us that fifty percent of long-term care residents require dentures, but without some sort of cost factor to associate with that statistic, it is impossible to reach meaningful conclusions about affordability of the "basket of goods and services" which might be considered medically necessary for residents. The tables in Appendix F provide a range of retail prices for common out-of-pocket expense items required by long-term care residents.

7.1 Analysis of Retail Pricing

The methods section of the paper highlights the impossibility of generalizing from unit price lists, or generating valid "average out-of-pocket costs," because of wide variability in the needs and usage of individual residents. The price list in Appendix F does serve, however, to illustrate the range of medically-necessary items and prices of items which commonly end up in a resident's "shopping basket," at quite a substantial cost.

Combining the retail prices with information from caregiver surveys and case study family expense diaries, a picture emerges of typical out-of-pocket costs which can easily exceed low-income residents' remaining income after per diems and room differentials are paid.

By way of illustration, I have generated below a table of expenditures for a hypothetical, but not "atypical", long-term care resident. My hypothetical resident is among the seventy-two percent of BC long-term care residents in the lowest income category. My hypothetical resident relies solely on OAS/GIS income of $1,032.45 per month and, after payment of the $854.71 monthly facility fee, has a total of $177.74 remaining to cover *all* other expenditures. The following table illustrates what I believe to be a conservative price list of monthly out-of-pocket expenditures.

Table 10: Hypothetical Out-of-Pocket Expenditures for a Typical Resident

Item or Service	Monthly Cost	Assumptions
Dentist	$33.00	Based on $400/year
Dentures	$33.00	Based on cost of $2000 for full 2-arch set replaced every 5 years
Denture Supplies	$15.00	Estimate from caregiver surveys
Optometrist	$7.50	Based on $90/year for one eye examination
Prescription Eyeglasses	$5.80	Based on lowest cost frames with plastic, scratch-coated bifocal lenses
Podiatrist	$40.00	Based on one visit every 4 to 6 weeks at $40 - $55/visit
Barrier Cream	$12.00	Estimate from caregiver surveys
Prescriptions	$20.00	Estimate from expense diaries
Over-the-Counter Medications	$9.50	Assuming regular use of Tylenol, calcium, vitamin D, and laxatives
Special Clothing & Hip Protectors	$83.00	Assuming $200 /year for hip protectors and $800/year for special clothing
Audiologist	$3.13	Based on $75 fee for hearing test every two years.
2 Hearing Aids and Batteries	$30.00	Based on lowest cost, basic technology hearing aids at $850 each, replaced every 5 years
Toiletries	$10.00	Resident responsible for items like toothbrush, toothpaste, deodorant, skin cream, hair products, etc.
Clothing Labels	$2.08	Based on fee of $25
Compression Support Stockings	$28.00	Based on one pair per month non-prescription price
Total Out-of-Pocket Expense	**$332.01**	
Total Disposable Income	**$177.74**	
SHORTFALL	**$154.27**	**Note that the above costs do not include amortized costs for commonly purchased, expensive capital items like specialized wheelchairs, *or any discretionary monthly expenditures* for services like telephone or cable television, hairdressing and so forth.**

If these costs are unaffordable (based on residual income after per diems are paid) and the resident cannot or will not purchase the items, adverse impacts on health and quality of life could be significant. Some examples of potential adverse health impacts are as follows:

- Inadequate bowel care is known to increase the incidence of impaction;
- Inadequate Calcium and Vitamin D reduce the effectiveness of some osteoporosis medications leading to increased risk of fractures;

- Lack of compression support stockings can lead to circulatory problems and pulmonary embolism;
- Lack special cushions and mattresses can lead to pressure ulcers;
- Lack of mobility aids may lead increased risk of falls, and to decreased mobility and increased risk of pneumonia; and
- Lack of hip protectors increases risk of hip fracture

Recall that over seventy percent of residents have incomes in the lowest category, many relying solely on Old Age Security and Guaranteed Income Supplement payments totalling $1,032.45 per month. After payment of the lowest current per diem ($854.71 per month) remaining income to cover all other expenses is $177.74.[22]

Section 5 of this paper discusses the existence of a "needs fund" at one of the facilities surveyed, which speaks to the fact that residents cannot afford things they require. Free response comments from caregivers surveys also provided examples of residents not purchasing hip protectors, or specific prescription medications because of cost.

Inability to purchase items such as a preferred brand of incontinence briefs, or having to experience only one change of incontinence garment per eight hour shift may not create an actual health hazard, but could reduce self-esteem and/or quality of life. Grooming is important to self esteem, and typical hairdressing charges are $69.00 per month based on $16.00 per weekly service for women. Lack of companion or escort services may add to social isolation, but may also adversely affect nutrition if the companion's role is to encourage and or assist the resident to eat.[23, 24]

Many major capital cost items such as custom wheelchairs and special mattresses and cushions are far beyond the financial reach of low-income seniors in long-term care facilities. For the lowest income residents (comprising over seventy percent of all residents), purchase of items

---

[22] The selected typical expenditures itemized in Table 15 above, which totalled more than $330.00 per month, do not include room differentials, any recreation or outings, hairdressing, services such as physiotherapy, companion services, escort services to specialist appointments, or prorated costs of major capital expense items such as special mattresses and cushions, or custom wheelchairs. Clearly, when these items are added in, the affordability problem could be unmanageable, and needed items and services will not be purchased or will create financial hardship for the resident and/or family.

[23] Dr. Margaret McGregor's study of 167 BC nursing homes (published in the February 2005 Issue of the Canadian Medical Association Journal) found that the average staff hours per resident per day in for-profit facilities was 20 minutes less per resident per day for direct care staff, and 14 minutes less per resident per day for support staff; and that it takes 18 minutes for one staff member to provide feeding assistance to three residents at the same time. Some families pay outside caregivers to assist residents at mealtime.

[24] Case study respondents who completed 2-week expense diaries indicated that one of the functions of paid caregivers was to provide companionship during mealtimes and assistance with eating.

such as hip protectors and compression support stockings can create financial hardship. Inability to purchase these items may result in serious negative consequences in terms of health outcomes as discussed above. Some studies, like the 2004 study of falls conducted by the BC Provincial Health Officer suggest that adverse events attributed to underutilization of chargeable items like hip protectors may increase costs to the health care system.

As previously mentioned, medically necessary items and services which represent typical out-of-pocket expenditures to residents and families include eye examinations, prescription eyeglasses, dentistry, dentures, hearing aids and batteries, repair and maintenance of hearing aids, wheel chairs or other mobility aids and repair of same..[25] Many residents also require special footwear and clothing to prevent injury during dressing, prevent falls and so forth. Residents also have ordinary expenses like those incurred by any individual, including clothing, toiletries, and personal grooming expenses.

Virtually all of the above items and services appeared in expense diaries from my four case studies. The literature speaks to the high percentage of residents who require hearing aids, prescription lenses, dentistry, dentures, and mobility aids including hip protectors and wheelchairs. These expenses are all over-and-above per diems, room differential charges, transportation and recreation costs, physiotherapy, massage or other therapies, toiletries and items such as personal phone and cable television charges. None of these items are covered under provincial medical insurance.

Based on the cost of commonly-required items and services, controlled research studies could inform policy analysts on the benefit/cost projections for inclusion of select items and services in the basic service package provided under the residents' per diems.

[25] The cost for an eye examination is approximately $90. West End Optometry's current minimum cost charged to a senior for a prescription eyeglass package consisting of the lowest price frame and plastic, scratch-coated bi-focal lenses is $140.

8 Results from 3-Year Resident Billing Comparison

In light of significant changes to the delivery of long-term care in BC since 2002, one of the objectives of this study was to follow up on the prior HEU research which suggested that extra billing may be increasing in both for-profit and not-for-profit long term care facilities. Significant changes in the delivery of long-term care include: implementation of the new provincial access policy (PRAP) resulting in higher average acuity levels in long-term care facilities; delisting of a number of items and services from the provincial medical insurance plan; closure of hundreds of long-term care beds; passage of the *Community Care and Assisted Living Act;* and reduction in staffing levels of Registered Nurses with transfer of some responsibilities to patient care aids. This led me to attempt to obtain longitudinal data on out-of-pocket resident expenditures from 2002 forward, for comparison purposes, to determine whether or not extra billing trends within the sample facility could be identified. As a single case study, generalization of findings cannot be relied upon.

I had also hoped to make some comparison to the 1999 out-of-pocket cost data from Substudy # 5, but since the Hollander data included purchases outside the facility and the three-year billing records did not, no valid comparison was possible (Hollander et al., 2002).

My request for confidential access to long-term care facility billing information from files administered by the Public Guardian and Trustee of BC was denied. I contacted the proprietor of a lower-mainland long-term care facility to request three years of confidential billing records, and these records were graciously provided to me for inclusion in this study.

The methodology section of the paper discusses some of the difficulties in analyzing the data, including the reliability of "average" resident costs, and the lack of information regarding use of cash withdrawals from resident trust accounts.

The proprietor of a Vancouver-area for-profit long-term care facility provided me with records of facility billings (including pharmacy) to individual residents for the years 2002 – 2004. The three following tables summarize the total amount billed to residents each month for the three year period. Two categories of expenditure show dramatic increases over the period (foot

care and pharmacy billings), and others merit brief discussion for different reasons. The very low billing each year for dental care is one such category, and the decreasing cash withdrawal category is another.

Table 11: Summary of 2002 Resident Billings

Item or Service	Total 2002 Billings	Comments
Bake Sale	$275	
Cigarettes	$958	One client billed $79. All other bills were to one other name for $879
Clothing	$1,376	
Companion Services	$256	
Cash Withdrawals	$15,786	Most did not specify use. A few that specified were for taxi, UPS, fax, Handi-dart, tissues, meals and outings.
Dental	$1,050	All but 3 of these were $3.00 charges related to only about 7 service dates during the year. The 3 larger bills were for $35, $160, and $180.
Foot Care	$2,700	All charges were for $15, and related to 5 specific service dates during the year.
Hairdressing	$28,778	There were 1,799 separate billings
Miscellaneous	$2,935	Some items described were optical, ambulance, toothpaste and razors, support stockings, visitor meals, Avon and Mary Kay purchases.
Outings	$1,323	These bills related to four outings: one in February, June, October, and December. There were just over 20 residents billed for each outing, except one in February for which only 2 residents were billed. On several outings a few family members attended as guests, and a few residents had "companions" accompany them.
Podiatrist	$910	Majority of charges were for $20; a good number were also for $40; and a few were for $10.
Pub Night	$759	
Raffle Tickets	$90	These were always invoices
Recreation Charges	$16	These were 8 charges for $2 each for one isolated activity
Pharmacy	$24,905	
Shoes	$367	This was made up of 8 invoices to separate residents.
Supper Club	$2,188	Made up of many invoices. Monthly meals ranged from $5.50 to $6.50 per meal.
Ambulance	$54	A few ambulance charges also appeared in the miscellaneous category.
Tuck Shop	$1,981	
Total, All Categories	**$86,708**	

8.1 Resident Billings for 2002

Extra charges to residents of this facility in 2002 for all expense categories totalled $86,708. Based on nearly one-hundred percent occupancy this amounts to an average of just over $58 per month per resident. This average, on its own, is not particularly useful, because there is great variability in expenses amongst residents. (In the pharmacy category, for example, some residents were billed nominal amounts in the range of a few dollars a year, whereas others' bills amounted to many hundreds of dollars based on the items and medications purchased.) The data can be used, however, as a benchmark to measure change in total resident billings and in specific expenditure categories over the three year period from 2002 to 2004.

By far the largest billing categories in 2002 were Hairdressing at $28,778 (thirty-four percent of charges), Pharmacy at $24,905 (twenty-nine percent of charges), and Cash Withdrawals at $15,786 (eighteen percent of charges). The rest of the items combined totalled $17,239 – under twenty percent of total charges.

Very little information is available itemizing what type of expenditures were made from cash withdrawn. As will be seen in subsequent tables, this is one major billing category where expenditures decreased over the three-year period, which is difficult to explain without knowing what the money was used for.

Table 12: Summary of 2003 Resident Billings

Item or Service	Total 2003 Billings	Comments
Bake Sale	$73	
Cigarettes	$491	One resident invoice $405 and one other $86
Clothing	$999	
Companion Services	$152	
Cash Withdrawals	$11,353	Few itemized. Some were for Handi-dart, outings, taxi fares
Dental	$85	One invoice
Foot Care	$1,974	110 invoices. 20 were for $15 in January, and the rest were for $18 for later months.
Hairdressing	$31,779	There were 2,022 invoices
Ice Cream	$227	
Clothing Labels	$1,375	54 invoices for $25 each
Miscellaneous	$711	Few itemized. Some were for medical supplies like support stockings; pharmacy, meals, Mary Kay, Shaw Cable charges.
Outings	$1,674	Numerous outings range of prices between $4 and $30. One or 2 outliers of individual bills > $30
Podiatrist	$540	27 invoices at $20 each
Pub Nights/Afternoons	$682	
Raffle Tickets	$110	
Pharmacy	$29,008	1,571 individual invoices ranging from $1 to $212 each. (A few pharmacy billings showed up under other categories such as miscellaneous.)
Shoes	$307	6 invoices to separate residents
Supper Club	$1,031	Several occasions ranging in price from $5.50 - $10.
Tuck Shop	$1,964	
Total, All Categories	**$84,535**	

8.2 Resident Billings for 2003

Extra charges to residents in 2003 for all expense categories totalled $84,535, which represents a drop in billings to residents of $2,173, amounting to a 2.5 percent decrease from 2002. This brings average resident billings to just under $57 per month for 2003. Again, average numbers are not particularly meaningful due to large variability in billings amongst residents.

As was the case in 2002, by far the largest billing categories were Hairdressing at $31,779 (a ten percent increase over 2002), Pharmacy at $29,008 (a 16.5% increase over 2002), and Cash Withdrawals at $11,353 (a twenty-eight percent decrease from 2002). Because there is almost no information on uses of cash withdrawals, it is difficult to determine why amounts in this category have decreased. All billings for other items combined totalled $12,395 – under fifteen percent of total charges. The 16.5 percent increase in pharmacy charges is worth noting. It is somewhat difficult to interpret due to the number of factors which could influence costs. Medications could have been placed on or removed from the provincial formulary, new treatments could have become popular, older and frailer residents could have higher healthcare and medication needs.

Dental, Foot Care and Podiatrist billings continue to be minimal. One explanation is that residents and their families pay out-of-pocket for services outside the facility or to bring the services in. A new category called "Clothing Labels" appears in the 2003 billings. Fifty-four residents were each charged $25 to have identification labels sewn into their clothing.

Table 13: Summary of 2004 Resident Billings

Item or Service	Total 2004 Billings	Comments
Taxi	$111	4 invoices
Cigarettes	$1,159	One person charged $1,002 and 1 other invoiced $157
Clothing	$2,764	
Companion Services	$411	
Cash Withdrawals	$9,271	Few itemized. Some were for meals, postage, soft drinks, Handi-dart, a fan, and several $25 donations to the Alzheimer's Society
Dental	$1,040	This as 26 invoices for $40 each in September
Foot Care	$11,896	This included 651 billings. The majority were for $18 each, and a small number were for $28.
Hairdressing	$32,840	There were 2,036 invoices
Ice Cream	$432	
Clothing Labels	$1,000	40 invoices for $25 each
Miscellaneous	$2,414	Few itemized. Some were for bazaar sales, soft drinks, meals, optical, support stockings, Handi-dart, denture supplies and unspecified medical supplies. Four were for massage therapy, costs from $30 - $55. Eighteen were for wheelchair or walker repairs/service (total of $414 for the 18 bills, averaging $25).
Outings	$3,168	Numerous outings. Cost ranged from low of $4 to high of $35 per outing.
Pub Nights/Afternoons	$471	
Raffle Tickets	$515	
Photo Envelopes	$60	
Pharmacy	$39,112	
Shoes	$606	14 invoices
Supper Club	$1,205	Several occasions ranging in price from $6 to $10
Transport	$75	1 invoice
Tuck Shop	$2,594	
Total, All Categories	**$111,144**	

8.3 Total Resident Billings for 2004

Extra charges to residents in 2004 for all expense categories totalled $111,144, which represents an increase in billings to residents of $26,609, amounting to a dramatic increase of just under thirty-two percent from 2003. Average resident billings rose to $75 per month, up from $57 per month in 2003.

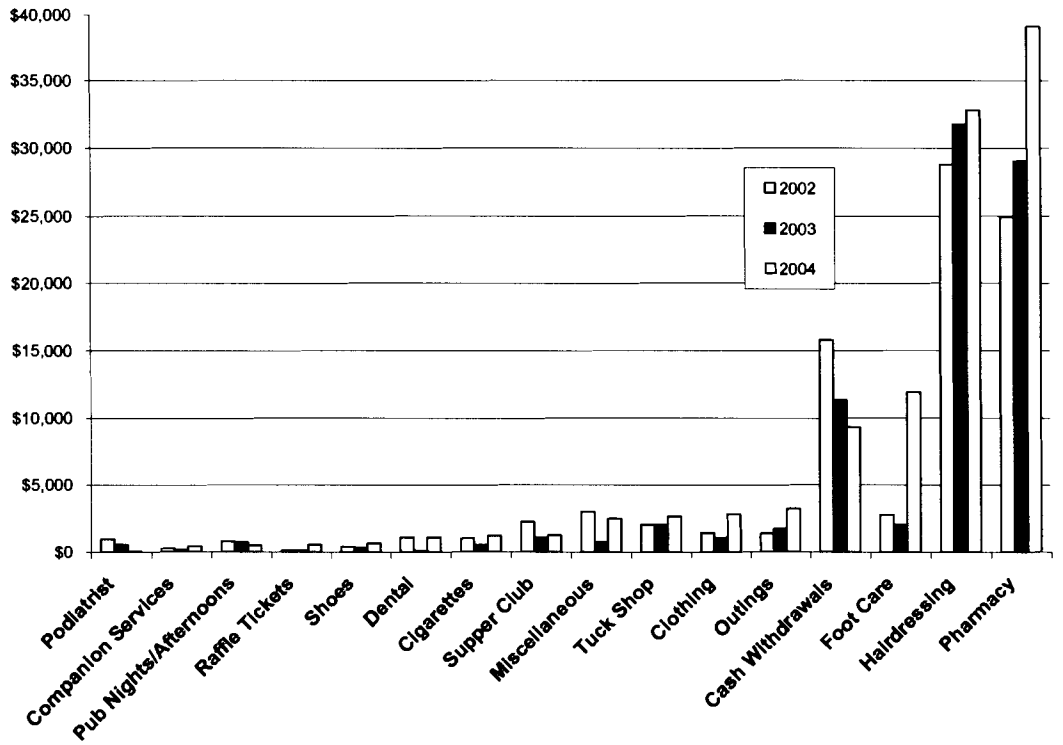
For the first time in the three year period, Pharmacy billings accounted for the greatest percentage of total billings, at $39,112 (a thirty-five percent increase over 2003 pharmacy charges). Hairdressing accounted for total billings of $32,840 (a three percent increase over 2003 charges), and the foot care category rose significantly to $11,896 from $1,974 the previous year (a 503% increase).

Cash Withdrawals decreased once more in 2004, to $9,271 (an eight percent drop from 2003). Again, this is a difficult category to interpret, since there is no indication what purchases are made with the withdrawn funds.

Billings for dental care remain insignificant, at $1,040. Forty residents were billed $25 each to sew identification labels into their clothing.

Although it is difficult to draw too many conclusions from aggregate and average billing data, the pharmacy billing category stands out as an area in need of further research because the rise in billings from $24,905 in 2002 to $39,112 in 2004 represents a fifty-seven percent increase over this short period under study. The following Figure 4 graphically illustrates the changes in billings in the facility over the three year period.

Figure 4: Total Resident Billings 2002 – 2004 for One For-Profit Long-Term Care Facility



8.3.1 Billings for Dental Care

On first reviewing resident billings, dental care might escape notice because it is such a small dollar figure in each of the three years. On reflection, however, it becomes evident that dental care is a huge concern in long-term care facilities. As documented earlier in this paper, many long-term care residents have dental health problems, including missing teeth, and many rely on dental prostheses. The lack of billing for dental care by the facility raises the question of what is supplied and paid for by long-term care facilities, and how needed dental care is accessed by residents in general, and by low-income residents in particular.

8.3.2 Pharmacy Billings

The absolute dollar increase in total pharmacy billings to residents is very dramatic over the period, with the 2004 billings of $39,112 representing an increase of just over fifty-seven percent over 2002 pharmacy billings. This $39,112 in billings represents an average pharmacy billing per resident of $26.29 per month, up from average billings per resident of $16.74 per month in 2002.

I did not have access to itemized billing information detailing items and medications purchased, so I could not determine from this data whether or not items such as glucose monitoring strips, complex dressings, laxatives, mobility aids and other items and medications mentioned in staff interviews from the eight surveyed facilities (examined in the caregiver interview section) were included in these billings. *There is great variability in pharmacy charges depending on resident needs, so average charges should be interpreted with caution. As well, there is variability in income levels of residents, with potential negative impacts of increasing out-of-pocket charges likely to be influenced by resident income.*

There could be numerous confounding variables which influence billings, and as noted previously, this is an area which requires additional study. It is generally agreed that one of the largest drivers of cost-increases in the healthcare system nation-wide is the increasing cost of prescription medication. Other factors are at play here as well. Earlier sections of this paper have documented and explained the increasing number and acuity of health problems experienced by residents entering residential long-term care. As well, those residents who are ageing in place in the facilities may have increasing health problems and require additional medication. New treatments or medications may have been added to the list of items used by residents, and some specific items or medications could have been among those removed from the provincial formulary making them uninsured and subject to payment by the individual residents.

Another complex issue for future research on out-of-pocket pharmacy costs, is whether the items and medications prescribed result in better health outcomes and fewer adverse effects, thus lowering the overall cost to the healthcare system due to reductions in acute care hospital admissions.

The proprietary facility which provided the resident billing data had a near one-hundred percent occupancy rate over the three-year period, with no new beds added. Therefore, what can be said with certainty is that the "average" billing per resident has increased substantially over the three-year period – far in excess of the increases in income of the lowest income residents through adjustments in pension and supplement income based on increases in the consumer price index. Recall that facility per-diems have been indexed to inflation, and have increased slightly as well. As data was derived from only one case study, these results cannot be generalized.

9 Conclusions

9.1 Information Gathering Methodology

Study Question: What is the most efficient and effective method of gathering information regarding out-of-pocket charges to residents of government-funded long-term care facilities in BC?

The methodology section of the paper details weaknesses in each of the five information gathering methodologies employed in the study. In order to obtain a reasonably clear picture of the extra billing situation in BC's long-term care facilities, information from all five research tools (supported by evidence from the literature) was required to provide a level of comfort with the validity of findings.

My conclusion is that there is currently no efficient and effective method of gathering information on out-of-pocket charges in BC's government-funded long-term care facilities. What is required, is a comprehensive reporting and accountability requirement to be written into funding agreements for all government-funded facilities.

9.2 Variability Amongst Facilities in Application of Out-of-Pocket Charges

Study Question: Is there variability amongst government-funded long-term care facilities in the application of out-of-pocket charges to resident?

Combined information from government documents, the literature review, key informant interviews, caregiver telephone surveys, and case study expense diaries allows me to state with certainty that there is great variability amongst facilities in the application of out-of-pocket charges. The range includes, among other things, large discrepancies in room differential charges, variation in co-payments for medications, and application of fees for therapeutic and recreational services.

9.3 Patterns of Out-of-Pocket Charges Based on Facility Ownership Type (for-profit versus not-for-profit)

Study Question: Are there significant differences in extra charges based on facility ownership (for-profit versus not-for-profit)?

Although the previous HEU study of select BC facilities indicated that there were differences between the for-profit and not-for-profit facilities, with for-profits charging residents larger amounts for a wider range of items and services, evidence from my current research was much less definitive. The HEU study indicated that funding constraints and ongoing changes to the long-term care delivery sector might lead to increased charges in not-for-profit facilities as well as for-profits., Findings from the current study were inconclusive. More research is required before any conclusion can be reached regarding significant differences in extra billing practices based on ownership type.

9.4 Impacts of Out-of-Pocket Charges on Quality of Life and Health Outcomes for Residents

Study Question: What are the potential impacts of out-of-pocket charges on quality of life and health outcomes for residents?

Evidence from the literature, government publications, and the responses to caregiver telephone surveys and case study expense diaries confirms that out-of-pocket charges are creating hardship for some residents and their families. More research is required to determine the severity of the problem and the prevalence and nature of any impacts on quality of life and health outcomes for residents. The vast majority of long-term care residents have very high needs, and very low incomes. Evidence of a serious problem is contained in recent provincial studies on poor dental health and the high incidence and high cost of falls resulting in hip fractures in long-term care facilities. Other specific examples of hardship were provided in caregiver survey responses.

9.5 Impacts of Out-of-Pocket Charges on Costs to the Healthcare System

Study Question: What are the potential impacts of out-of-pocket charges on costs to the healthcare system?

More study is required to determine the impacts of out-of-pocket charges on costs to the healthcare system. Disturbing statistics regarding the high incidence in long-term care facilities of poor dental health and frequent falls resulting in serious injury support a recommendation to conduct controlled experiments to assess methods to mitigating these problems.

At least one caregiver survey response pointed to a situation where imposition of extra charges resulted in added cost to the healthcare system. The example involved a facility that, for a time, stopped providing laxatives free of charge, then reversed that policy when it became evident that acute care hospital admissions for bowel impactions increased due to reduced usage correlated with out-of-pocket cost.

Generalizing from a substantial body of literature which shows a negative correlation between patient cost and usage of medically necessary items and services, it is reasonable to hypothesize that there is a high likelihood that unaffordable of out-of-pocket charges could reduce usage of such items as hip protectors, physiotherapy and dentistry, and that *net costs*, rather than a *net savings* to the healthcare system could result.

Caregiver survey responses document reduced usage. More study is required to determine budgetary impacts of adverse outcomes.

10 Policy Recommendations

Three recommendations flow from the study conclusions. The recommendations advanced below address gaps in four long-term care policy areas: information, accountability,consistency and efficiency. Each recommendation will be followed by a brief description of the policy problem or gap, and how well the proposed policy stands up to the standard criteria against which the recommendations were tested. These include efficiency, equity, infrastructure capacity, budget constraints, and political feasibility. It is highly unlikely that there will be resistance from the public politicians to the recommendations, which address increases in accountability and access to information, standardization of services, and evidence-based research to inform government policy. Therefore political feasibility of all three options is presented as a given.

It should be noted that the equity issue is complex. Recall that many frail elderly BC residents do not reside in long-term care facilities, but rather are cared for in the community by informal caregivers (including family members) and home support workers. Any study regarding provision of additional government-funded items and services to the long-term care cohort resident in provincial facilities, may have similar application to long-term care residents living in the community. Other areas for analysis include the issue of the fairness of reliance on family members or prior savings to fund current long-term care needs over and above per diem charges. These issues are beyond the scope of this paper, but are valuable questions for further study.

10.1 Recommendation # 1

> that contractual reporting and accountability requirements (documenting items and services provided without charge as well as those billed to residents).be written into funding agreements between health authorities and long-term care service providers; and further, that a monitoring system be designed and implemented.

This recommendation will address the problem of lack of information regarding the prevalence of extra billing, and the types of items and services residents must pay for out-of-

pocket. The reporting requirement would fall short of its objective if facilities were not required to report what items and services *are* provided to residents without extra charge. Many required items and services are purchased outside of facilities, and are not captured in facility billing records. The total out-of-pocket expenditures of residents include extra billings by the facility plus outside purchases. These outside purchases may include costly capital items like wheelchairs and roho cushions; therapeutic and preventative services like podiatry and dentistry; other medically-necessary items such as glucose monitoring strips and support stockings, and ordinary day-to-day daily living expenses such as specialized clothing and toiletries.

Table 14 below speaks to how well the recommendation number one meets the test of several standard public policy criteria.

Table 14: Justification for Recommendation # 1Based on Standard Criteria

Efficency	Equity	Infrastructure Capacity	Budget Constraints
▪ **Improves efficiency of gathering out-of-pocket expenditure data** ▪ **If required, government could assist with the development of standardized reporting software for facilities.**	▪ **Facilities would have identical reporting requirements, so amongst facilities is achieved.** ▪ **Information gathered would assist in monitoring compliance with recommendation 2.**	▪ **Very little need for additional infrastructure Computerized . bookkeeping systems already in place in facilities, and government financial reporting systems could be modified at minimal costs.** ▪ **Small additional # of FTE's might be required for monitoring function.**	▪ **Costs to implement should prove minimal, and would include modification of current government electronic and paper financial systems and a minimal number of additional FTE's for monitoring function.**

10.2 Recommendation # 2

> that the Ministry of Health Services move to standardize the items and services provided without extra charge to residents of all government-funded long-term care facilities in BC.

This recommendation will address the current problem wherein comparably-funded facilities serving similar residents charge different amounts for the same items and services. The amount a resident pays for room differentials (and many items and services) varies from facility

to facility. Out-of-pocket costs are dependent upon where the first appropriate bed becomes available when they meet eligibility criteria for placement.

Standardization of insured items and services might be achieved either by bringing all facilities under the jurisdiction of one legislative act, or by making necessary amendments to one or both existing acts to eliminate differences in billing procedures. It is beyond the scope of this study to determine the best method of achieving standardization.

Table 15 below illustrates how well the recommendation number two meets the test of several standard public policy criteria.

Table 15: Justification for Recommendation # 2 Based on Standard Criteria

Efficency	Equity	Infrastructure Capacity	Budget Constraints
▪ Standard regulations reduce complexity of administration. ▪ Standardization enhances efficiency of other initiatives like controlled research experiments.	▪ Standardization ensures similar goernment facilitis provide identical insured services to residents.	▪ Capacity already exists to implement standards. ▪ Several additional FTE's may be required for monitoring compliance. ▪ Minor modifications of reporting procedures and software may be required.	▪ Standardizing room differentials will result in less revenue-generating potential for Hospital Act-designated facilities, or increased revenue-generating potential other facilities. As new facilities are constructed to complex care standards all rooms will be single rooms in any event, with no room differentials charged. ▪ If other facilities offer therapies and items such OTC medications without charge as in Hospital Act-designated facilities, expenditures will rise for non-hospital facilities.

10.3 Recommendation # 3

that the Ministry of Health Services commence controlled research trials in the form of pilot projects, to inform policy regarding which items and services should be provided without charge to long-term care residents. (Study results indicate that two priority research areas/pilot studies are: a) the efficacy of providing free hip-protectors as a method of reducing hip fractures in facilities, and b) a benefit/cost analysis of providing free dental care in facilities.[26]

[26] The justification for prioritizing two specific pilot studies flows from studies documenting extremely high incidence of falls and hip fractures, and poor dental health amongst BC's long-term care residents. Based on a preliminary cost analysis of the financial savings which might be realized from increased use of hip protectors by long-term care residents, this pilot study, in particular, could demonstrate a useful

Table 16 below illustrates how well recommendation number three meets the test of several standard public policy criteria.

Table 16: Justification for Recommendation # 3 Based on Standard Criteria

Efficiency	Equity	Infrastructure Capacity	Budget Constraints
▪ Long-term care facilities are an ideal site for efficient controlled experiments/pilot studies of this nature. Detailed patient records are already maintained and there is twenty-four hour monitoring. ▪ Comparative statistics would be readily available. ▪ Information gathered from research could be applied to increase efficiency in the overall health care system. For example, if providing hip protectors without charge to residents of long-term care facilities reduces overall cost to government by reducing the incidence of hip fractures, efficiency gains could be substantial.	▪ Equity is not at issue in controlled research trials. ▪ Equity in insured services between facility and community residents could become an issue if trials result in policies to provide additional items and services to long-term care facility residents.	▪ Would vary with each individual research trial. For instance, additional staffing might be required to ensure proper use of hip protectors. ▪ Detailed patient records already maintained, so this aspect of pilot studies would not strain existing capacity.	▪ Would vary with each research trial. ▪ Fairly small scale pilot projects could yield inexpensive, but generalizable results. ▪ Research grants are likely to be available to help fund trials ▪ Potential for partnership funding for research exists.

10.4 Relationship of Policy Recommendations to Study Objectives

The three policy recommendations speak directly to the objectives of this study. The research conclusion is that ,of the current methods for gathering information regarding out-of-pocket charges to residents of government-funded long-term care facilities in BC, none is efficient or effective.

Recommendation # 1 creates an alternative which is both efficient and effective. The research conclusion regarding variability amongst government-funded long-term care facilities in the application of out-of-pocket charges to residents, is that great variability exists within the system

Recommendation # 2 eliminates variability through the imposition of standards which apply to all government-funded facilities throughout the provincial system. The conclusion

---

template for benefit/cost analysis of incorporating various items and services in the provincial medical insurance plan. Experts in the field of gerontology could recommend other research projects to help inform policy makers.

regarding potential impacts of out-of-pocket charges on quality of life and health outcomes for residents, and for costs to the healthcare system, is that more evidence-based research is required.

Recommendation # 3 proposes a framework for gathering evidence-based information to guide policy which optimize quality of life and health outcomes for residents within provincial health care budget constraints.

Appendices

Appendix A: Data Bases and Search Terms for Literature Review

Data bases:

- Medline
- PsychINFO
- CINAHL
- HealthSTAR
- Social Science Abstracts
- Sociofile
- AgeLine
- Health Source

Continuing Care Search Terms:

- Facility Care
- Chronic Care Facilities
- Personal Care Facilities
- Extended Care Facilities
- Long-term Care Facilities
- Nursing Home Facilities
- Skilled Nursing Facilities
- Palliative Care.

Funding terms:

- Cost Allocation
- Cost Sharing
- Deductibles and Co-insurance
- Capitation Fee
- Insured Service
- Uninsured Service
- Fee-for-Service
- Rate Setting
- Reimbursement
- Long-Term Care Insurance
- User-Pay
- Private-Pay
- Resident Fee
- Ancillary Services
- Out-of-Pocket Expenses

Appendix B: Literature/Studies on Impact of Out-of-Pocket Costs on Use of Medication and Services

Title Author	Objective or Theme	Subjects Size	Location/Date	Methodology	Conclusions	Comments
Adverse Events Associated with Prescription Drug Cost Sharing Among Poor and Elderly Persons By Robyn Tamblyn	• Determine the impact of introducing cost sharing on drug use among elderly and poor. • Determine rates of adverse events associated with reductions in drug use before and after policy implementation.	• Random sample of 93, 950 elderly persons and 55, 333 adult welfare medication recipients.	• Quebec • Data from approximately December of 1993 to January of 1998.	• Analysis of four Quebec health data bases including beneficiary demographics; prescriptions claims; physician claims and hospitalization claims.	• Cost sharing reduced use of less essential drugs and essential drugs. • Increase rate of adverse events in emergency department visits. • Cost sharing may contribute to avoidable illness.	• Recent Canadian data. • Some relationship to out-of-pocket costs but not facility related.
Income Based Drug Benefit Policy: Impact on Receipt of Inhaled Corticosteroids Prescriptions by Manitoba Children with Asthma By Anita Kozyrskyj	• Determine effects of income based deductible on prescriptions for inhaled corticosteroids by Manitoba children with asthma.	• 10, 700 school aged children	• Manitoba • Publication year, 1996	• Analyze data from four Manitoba Health Service Insurance Plan data bases.	• Post policy children with severe asthma less likely to receive inhaled corticosteroids prescription. • Lower use is associated with increased hospitalization rates.	• Recent Canadian data. • Children not elders. • Relates out-of-pocket costs to usage of a medically necessary prescription.
Socioeconomic Status, Drug Insurance Benefits and New Prescriptions for Inhaled Corticosteroids in School Children with Asthma By Anita Kozyrskyj	• Determine whether receipt of inhaled Corticosteroids in asthmatic children relates to socioeconomic status and type of drug insurance.	• 12, 481 school aged children.	• Manitoba • Data from July 1995 to March 1998	• Analyze data from four Manitoba Health Service Insurance Plan data bases to compare higher income children with lower income benefits and First Nations' benefits children.	• Low income asthmatic children are significantly less likely to receive to inhaled corticosteroid prescriptions even when prescription is no charge.	• Recent Canadian data. • Children not elders. • Not facility specific.
Effects of Limiting Medicaid Drug-Reimbursement Benefits on the Use of Psychotropic Agents and Acute Mental Health Services by Patients with Schizophrenia By Stephen Soumerai et al.	• Examine effects of payment cap for psychotropic drugs and acute mental healthcare on low income non-institutionalized schizophrenics.	• 268 study patients and 1959 controls. • all were permanently disabled non-institutionalized schizophrenics aged 19-60 years, insured by Medicaid.	• New Hampshire and New Jersey, USA. • Publication year, 1994. • Data pre 1987.	• Interrupted time series regression analysis of Medicaid claims was used to estimate effects of the cap.	• Increased mental healthcare costs for patients during the cap exceeded savings and drug costs by a factor of seventeen.	• Dated US data • Mental health patients, not seniors. • Not facility specific. • Relates use to out-of-pocket costs.

Title/Author	Objective or Theme	Subjects/Size	Location/Date	Methodology	Conclusions	Comments
Effects of Medicaid Drug Payment Limits on Admission to Hospitals and Nursing Homes By Stephen Soumerai et al.	• Determine if limited access to medications relates to increased rates of admission to nursing homes and hospitals.	• 411 New Hampshire study patients and 1375 New Jersey patients aged 60+.	• New Hampshire and New Jersey, USA • Publication year, 1991. • Data pre 1987.	• 36 months of Medicaid claims data were analyzed using segmented time series regression models.	• Strong indication of direct relation between drug reimbursement limit, reduction in use of medication and approximate doubling of rate of nursing home admissions.	• Dated US data • Relates to seniors. • Relates out-of-pocket costs to usage.
Payment Restrictions for Prescription Drugs Under Medicaid: Effects on Therapy, Cost, and Equity By Stephen Soumerai et al.	• Examine effects of drug payment cap on use of medications.	• 10, 734 New Hampshire Medicaid patients.	• New Hampshire, USA. • Publication year, 1987. • Data pre 1987.	• Time series analysis of Medicaid claims data.	• Cap is associated with significant reduction in use of several important medications including insulin.	• Dated US data. • Not senior specific. • Not facility related. • Relates costs to usage.
The Impact of Pharmacotherapy Policy: A Case Study By Robyn Tamblyn	• Study the impact of introduction of co-insurance and deductible cost sharing policy in Quebec on people 65+ and those on income security.	• 93, 950 seniors and 55, 333 income security recipients.	• Quebec • Data approximately from December 1993 and January 1998.	• Time series analysis of monthly drug use data.	• Policy reduced prescription use by 9.1% in seniors and 15.9% in income security recipients. • Increased monthly rate of emergency departments visits by 43% in seniors and 78% in income security recipients. • Adverse events doubled in the elderly population and increased by 88% for income security recipients.	• Canadian data. • Includes seniors. • Relates cost to usage.
Pharmacy Benefits and Use of Drugs by the Chronically Ill By Dana Goldman et al.	• Determine how changes in cost sharing effect use of the most commonly used drug classes among the privately insured and chronically ill.	• 30 large US employers covering 528, 969 beneficiaries for four years.	• USA • Data from 1997-2000. • Publication date, May 2004	• Analyzing data with multivariate regression and other statistical means.	• Larger burden of pharmacy costs are shifting to beneficiaries. • Medications needed intermittently are sensitive to co-payment charges. • Other medications for chronic illness show modest reduction in use. • Concern about adverse health consequences due to large price effects, particularly among diabetics.	• US data. • General, not seniors. • Not facility related. • Relates cost to usage
Patient Co-Payment and Use of Prescription Medicines By Evan Doran et al.	• Investigate how prescription co-payments influence medical consultation and prescription collection in Australia.	• 442 general practice patients.	• New South Wales, Australia. • Publication date, February 2004.	• General practice patient survey.	• 26% delayed visiting a doctor, 20% did not buy all prescriptions, 18% did not refill prescriptions due to cost. • Households with Children twice the odds of having difficulty due to cost.	• Australian data. • General, not seniors. • Not facility based. • Relates cost to usage

Appendix C: Experts Consulted

I spoke with the following researchers in the area of long-term care regarding possible data sources or relevant recent studies:

- Dr. Janet Fast, University of Alberta Department of Human Ecology;
- Wendy Armstrong, University of Alberta;
- Dr. Daniel Cohn, Assistant Professor, Political Science Faculty, Simon Fraser University;
- Dr. Olena Hankivsky, Associate Professor, Political Science, Women's Studies, and Public Policy, Simon Fraser University; and
- Dr. Jo Ann Miller, Director of Research and Evaluation for Hollander Analytical Services Ltd., Victoria BC.

Appendix D: Key Informant Interviews

I conducted interviews of the following key informants for this study:

- Karen Archibald, Manager of Information and Policy for the Home and Community Care Division of the Ministry of Health Services;
- Nancy Rigg, Executive Director of the Community Care Network from the Regional Office of Vancouver Coastal Health (VCH);
- Linda Thomas, Director of Residential Care and Assisted Living Facilities for Vancouver Coastal Health;
- Linda Rose, Director for VCH Directly-operated Long-Term Care Facilities; and
- Ed Helfrich, Executive Director of the BC Care Association.

Open-ended personal interviews were conducted with Linda Thomas, Linda Rose, and Nancy Rigg. Open-ended telephone interviews were conducted with Karen Archibald and Ed Helfrich.

Appendix E: Retail Pricing Sources

A range of prices for numerous health-care related items and equipment was developed by pricing retail items in person at Shoppers Home Healthcare (as suggested by several physiotherapists in Vancouver facilities), and viewing on-line catalogues from several other suppliers. A price list for over-the-counter medications and several other items was developed by pricing retail items in person at Shoppers Drug Mart. 2003 Price ranges for hearing aids were retrieved from the web site of the British Columbia Association of Speech/Language Pathologists and Audiologists. Eye examination costs and a prescription eyeglass estimate were obtained from West End Optometry. Denture cost estimates were provided by the Vancouver Centre Dental Clinic (based on the BC Dental Association Fee Guide), and from the Denman Denture Clinic.

Appendix F: Price Ranges for Common Out-of-Pocket Expense Items

Bowel Care Items	Cost Range		
	Low	Medium	High
Fruit Laxatives	Safeway Brand Fibre Supplement ($1.39/100grams).	Metamucil Orange Flavour ($1.77/100 grams). Safeway Brand Orange Flavoured Fibre Supplement ($1.83/100 grams).	Regular Metamucil ($2.26/100grams). Orange Flavour Prodiem ($3.31/100 grams).
OTC Laxatives	Senna –Safeway Brand (9.0 ¢/tablet).	Senokot (12.0 ¢ /tablet).	Woman's Laxative Tablets (17.3¢ /tablet). Ex-Lax-Regular Strength (28.3¢/tablet)
Enemas	130mL Life Brand (Regular) for $5.99	130mL Fleet Brand (Regular) for $6.49	130mL Fleet Brand (Mineral Oil) for $10.49.
Suppositories	60 tablets of Dulcolax (23.4 ¢/ tablet-5mg).	30 tablets of Dulcolax (26.7 ¢/tablet-5mg).	12 tablets of Safeway Brand (33.3 ¢/tablet-5mg). 10 tablets of Dulcolax (33.9 ¢/tablet-5mg).

Medical Supply Items	Cost Range		
	Low	Medium	High
Large Dressings	$16.20 for a box of 10 bandages, size 10 cm by 10 cm. (Non-medicated).		$20.63 for a box of 10 bandages, size 10 cm by 10 cm. (Medicated).
Barrier Creams		$5.49 for 50 grams	
OTC Imodium	6 tablets Safeway Brand (69.9¢/tablet).	12 tablets Imodium (91.0¢/tablet).	6 tablets Imodium ($1.20/tablet).
OTC Tylenol	100 tablets Safeway Brand Acetaminophen (3.7¢/tablet-Regular Strength). 100 tablets Safeway Brand Acetaminophen (4.3¢/tablet-Extra Strength).		100 tablets Tylenol (7.8¢/tablet-Regular Strength). 100 tablets Tylenol (8.7¢/tablet-Extra Strength
OTC Gravol	10 tablets Safeway Brand Travel Tabs (21.9¢/tablet-50mg).	10 tablets Gravol (31.1¢/tablet-50mg).	10 tablets Gravol (51.9¢/tablet-75mg).
OTC Calcium	100 tablets Jamieson at 650mg (10¢/tablet).		60 tablets Life Brand at 600mg (14.2¢/tablet).
OTC Iron Supplement	100 tablets Safeway Select (5¢/tablet).		Matlevol ($11.49/bottle-liquid).
Oxygen			
Tank		$5.00 rental/month	
Oxygen		$23.00/fill	
Regulator		$15.00	
Nasal Prongs		$3.00	

Medical Supply Items	Cost Range		
	Low	Medium	High
OTC Vitamin D	100 tablets Life Brand at 1000IU (5¢/tablet).		100 tablets Jamieson at 1000IU (6¢/tablet).
Glucose Monitoring Strips	$89.99 for 100 strips		$1.00 each
Nutritional Supplements			
Ensure	$20.99 for 12 cans		$2.29 each
Life Brand	$15.99 for 12 cans		$1.79 each
Glucerna	$22.99 for 12 cans		Cost not available per can.

Skin Care Items	Cost Range		
	Low	Medium	High
Special Mattresses	$250.00	$585.00	$10,000.00
Air Mattresses	$350.00		$10,000.00
Roho Cushions	$580.00		$860.00
Egg Crate Mattresses		$230.00	
Compression Support Stockings	$27.99 (over the counter).		$150.00 (Prescription).
Hip Protectors	$101.99		$119.99

Mobility Aid Items	Cost Range		
	Low	Medium	High
Wheelchair (the store only carried lower range chairs).			
Transport Chair	$199.99		$379.00
Push Chair	$399.00	$999.00	$1500.00
Power Chair		$4000.00 (the only power chair they carry).	Custom chairs in excess of $6,000.00
Walker	$79.99	$399.00	$550.00
Cane	$19.99		$39.99
Crutches		$39.99	
Bedside Assist Bar		$79.99	
Raised Toilet Seat	$28.99		$109.99
Reachers	$11.99		$40.99
Lift Chair	$799.00		$1300.50
Transfer Belts	$15.99		$69.99
Bathtub Bar	$74.99		$85.99
Scooter	$1299.00		$4999.00

Incontinence management Items	Cost Range		
	Low	Medium	High
Diapers			
Pull Up	$1.50 each		$2.00 each
Briefs	$1.00 each		$1.20 each
Night	$2.00 each		$2.10 each
Pads	$.50		$1.80 each

Incontinence management Items	Cost Range		
	Low	Medium	High
Incontinence Pads	$9.99 (for a pack of 25-disposable).		$24.99 each (washable).
Condom Drainage Bags	$5.99		$9.99
Urinary Catheter		$33.54 for 12	
Commode	$108.00		$399.00
Bed Alarm		$68.99	

Other Services	Cost	Details	Known Providers
Companion and Escort Services	Cost: $15-20/hour	Usually this takes up to 4 hours per appointment.	Three service providers: We Care, Abbott Senior Care and Bayshore Healthcare.
Ambulance Transport (if required)	Approx. Cost $54/trip	Some residents unable to use wheelchair, taxi or Handi-dart, so have to use ambulance.	

Podiatry Services	Cost
Foot-Care Nurse	$15/visit
Podiatrist	$40/visit

Hearing Aid Style	Basic Technology	Mid-Range Technology	Advanced Technology
Behind-the-Ear (BTE) and in-the-Ear (ITE)	$850 - $1500	$1350 - $2100	$2000 - $3200
Half-Shell (HS) and In-the-Canal (ITC)	$1000 - $1500	$1550 - $2300	$2100 - $3500
Mini-Canal (MC) and Completely In-the-Canal (CIC)	$1350 - $2000	$2000 - $2800	$2300 - $3500

Appendix G: Service Provider Questionnaire

Service Provider Questionnaire

Name of Facility: _____

Your Job Title: _____

How Long Have You Worked at This Facility? _____

How Many Hours/Month Do You Work On Site? _____

Extra Billed Items/Services:
Please Fill in the Charts Below Regarding Items/Services Which May Be Directly Billed to Residents (over and above the basic cost of accommodation and care).

Item or Service	Full Coverage	Partial Coverage	No Coverage	Has this Changed Since 2002?	Don't Know	Comments
Bowel Care:						
Fruit laxatives						
Over the counter laxatives						
Enemas						
Suppositories						
Ostomy supplies						

Has the cost of any of the bowel care items or services prevented a resident from accessing the item or service, affected care, or imposed a financial hardship?

_____
_____
_____
_____
_____
_____

Item or Service	Full Coverage	Partial Coverage	No Coverage	Don't Know	Has this Changed Since 2002?	Comments
Medical Supplies						
Dressing change trays						
Dressings						

Item or Service	Full Coverage	Partial Coverage	No Coverage	Don't Know	Has this Changed Since 2002?	Comments
Barrier Creams						
Over the counter Imodium						
Over the counter Tylenol						
Over the counter Gravol						
Over the counter Calcium						
Over the counter Iron supplement						
Other medications						
Oxygen						

Has the cost of any of the medical supply items prevented a resident from accessing the item, affected care, or imposed a financial hardship?

_____

_____

_____

_____

Item or Service	Full Coverage	Partial Coverage	No Coverage	Don't Know	Has this Changed Since 2002?	Comments
Ambulance Transport						
Taxi Transport						
Other Transport						

Has the cost of an ambulance prevented a resident from accessing ambulance transport, affected care, or imposed a financial hardship?

_____

_____

_____

Has the cost of taxi or other transport prevented a resident from participating in outings or trips?

_____

_____

_____

Does your facility have its own transport van? If so have uses or charges changed since 2002?

_____

Has the cost of prescription drugs prevented a resident from filling a prescription, affected care, or imposed a financial hardship?
(Was this a drug not covered by Pharmacare?

_____

_____

_____

Item or Service	Full Coverage	Partial Coverage	No Coverage	Don't Know	Has this Changed Since 2002?	Comments
Hypodermoclysis tubing						
Hypodermoclysis fluids						
Glucose monitoring strips						

Has the cost of any of the above prevented a resident from accessing the item, affected care, or imposed a financial hardship?

_____

_____

_____

_____

_____

_____

Skin Care	Full Coverage	Partial Coverage	No Coverage	Don't Know	Has this Changed Since 2002?	Comments
Special mattresses						
Air mattresses						
Egg Crate mattresses						
Roho cushions						
Compression support stockings						
Pressure ulcer treatments						
Hip protectors						

Has the cost of any of the above items or services prevented a resident from accessing the item or service, affected care, or imposed a financial hardship?

Mobility Aids	Full Coverage	Partial Coverage	No Coverage	Don't Know	Has this Changed Since 2002?	Comments
Podiatry services						
Wheelchair						
Walker						
Crutches						
Cane						
Floor to ceiling bar						
Bedside assist bars						
Raised toilet seat						
Bed alarm						
Lifts/lift slings						
Transfer belts						
Walking belts						
Other occupational aids						

Has the cost of any of the above items or services prevented a resident from accessing the item or service, affected care, or imposed financial hardship?

Incontinence Management	Full Coverage	Partial Coverage	No Coverage	Don't Know	Has this Changed Since 2002?	Comments
Diapers						
Incontinence pads						
Condom drainage bags						
Urinary catheters						
Portable Urinals						
Commode						

Has the cost of any of the above items prevented a resident from accessing the item, affected care, or imposed financial hardship?

Nutrition	Full Coverage	Partial Coverage	No Coverage	Don't Know	Has this Changed Since 2002?	Comments
Nutritional supplements						

Has the cost of nutritional supplements prevented a resident from accessing the item, affected care, or imposed financial hardship?

Recreation	Full Coverage	Partial Coverage	No Coverage	Don't Know	Has this Changed Since 2002?	Comments
Outings						
Within Facility Groups/Activities						

Has the cost of recreational activities prevented a resident from accessing the activity, affected care, or imposed financial hardship?

_____
_____
_____
_____
_____
_____

Companion Services	Full Coverage	Partial Coverage	No Coverage	Don't Know	Has this Changed Since 2002?	Comments
Paid companion						
Escort services to doctors' offices						

Has the cost of companion or escort services prevented a resident from accessing the service, affected care, or imposed financial hardship?

_____
_____
_____
_____

Use of Companions, Escort Services, or Outside Care Staff:
Do you have knowledge of residents who use/contract the services of outside paid help as companions, escorts, or care assistance?
_____yes _____no

If yes, how common is this practice? (i.e. approximately how many or what percentage or residents use paid outside help?)

_____
_____

If yes, what type of help is brought in by residents?
_____Paid Companion
_____Paid Escort

_____Other (please specify)

_____

What type of services are provided by outside helpers? (For example, feeding, shaving, socializing)

_____

_____

Are outside helpers generally employees of agencies, or private individuals?

_____

_____

Changes Over Time:

If you have knowledge of residents using outside paid help, in your view have the number of residents using outside paid help increased, decreased, or remained relatively constant since 2002? ___Increased ___Decreased ___Remained Relatively Constant

In your opinion are residents utilizing paid companions because they or their families have higher incomes, higher needs, both, or for other reasons?

_____

Extra Baths	Full Coverage	Partial Coverage	No Coverage	Don't Know	Has this Changed Since 2002?	Comments

Has the cost of extra baths prevented a resident from accessing the service, affected care, or imposed financial hardship?

_____

_____

_____

_____

_____

_____

Bathing Frequency	Once/Week	Twice/Week	More Frequently

Personal Out-of-Pocket Expenditures on Behalf of Residents:
Have you incurred out-of-pocket expenditures on behalf of residents?

If yes, what items/services did you provide?

What was the cost of items and services you provided?

Is there a resident charge for:
Hairdressing?_____
Shaving?_____
Shaving supplies?_____
Shampoo?_____
Toothbrush?_____
Toothpaste?_____

Additional Comments:

For RN's: Policy Regarding Resident Charges
Does your facility have a written policy regarding items and services charged to residents?
How does your facility determine what items/services are charged to residents, and amounts charged?

Appendix H: Case Study # 1

DESCRIPTIVE INFORMATION:

The family caregiver is under sixty-five years old, retired, the sole caregiver and the daughter of the resident. She resides three kilometres from the facility and visits daily. The age of the female resident is eighty-eight years. She has been a facility resident for twenty-nine months, and resides in a four-bed room.

The resident's approximate income is $4,333 per month, and per diem is $66.30 which averages $2,027 per month. There is no room differential paid.

Physical limitations include mobility, hearing, vision, and muscle control. The resident has a very soft voice, communication difficulties, and trouble with balance. The cognitive limitation is dementia. Chronic conditions are Parkinson's disease, thyroid problems, and dementia.

DIARY EXPENDITURES:

The two-week expense diary documented additional out-of-pocket expenditures of $448.05 for the period. These included four music therapy sessions at $50/session; three paid companion visits at $45/visit, one podiatrist appointment at $43.00; toiletries (body wash, tissues etc.) totalling $24.95, and transportation costs for the family member (including parking costs, using mileage rate of $0.45/km) of $45.10. Converted to a monthly expenditure this would amount to out-of-pocket costs of $970.78 per month. **Combined with the facility and room differential charges paid, this brings total monthly expenditures to $2,997.78. The resident's gross income is approximately $4,333 per month.**

AVERAGE EXPENDITURES, DECLINED EXPENDITURES AND HARDSHIP:

The respondent indicated that expenditures in the two-week diary under represent expenditures in an average two-week period. The following are explanatory comments:

> Under represent as many supplies are bought in bulk or when on sale and "delivered" to the resident as required. These include: hearing aid batteries, body wash, moisturizers for skin, hair products, tissue, food supplements such as snack portions of canned fruit, puddings, custards. Occasionally there are dry-cleaning expenses. The "normal" trip to the outside hairdressers (approx. average cost of $40/week) was not done during this two week period because of weather and non-availability of the hairdresser. Also, magazine purchases average $15 - $20 / month: these provide significant recreation/entertainment for my mom.

CD purchases – these are used to calm at bedtime and for dinnertime music for the dining area.

The respondent indicates that there are sometimes items/services which would be a health benefit to the resident which are not purchased or accessed due to cost. The explanatory comment was:

> Additional music therapy and companion services, especially companion services so that family caregiver could have more and lengthier "breaks". Have also considered private recreation and/or Art Therapy, however understand it is expensive and have not purchased it.

Although the response to the question of whether or not out-of-pocket costs of residential care had imposed hardship on the resident or family, the answer was no, however the comment was contradictory:

> No hardship yet. However, I have had to make significant choices regarding care giving that have significantly affected my career income and pension with very significant financial consequences. Anticipate that expensive private nursing may be required when my mom is in the "final stages", given the anticipated decrease in RNs.

CAPITAL EXPENDITURES, ADDITIONAL SERVICES AND GENERAL COMMENTS:

The respondent felt unable to cite the frequency of large capital expenditures, saying that these purchases vary greatly upon need. The largest capital expenditure was the cost of a specialized wheelchair for approximately $6,000. The specialized and transport wheelchairs, and several other expenditures were itemized as comments:

> The specialized wheelchair purchase was initially $6,000.00. The transport wheelchair cost $300.00. It is difficult to anticipate future needs such as wheelchair repair, different specialized seatbacks/cushions as mom's condition changes. Blackout curtains to block drafts and keep room cool in summer and warm in winter (facility is not air conditioned) cost $85.00, and electric fan for summer cost $75.00.

Additional services identified as paid for out-of-pocket included music therapy, podiatry, dentistry, companion services and hairdressing:

> Pay for music therapy twice a week at $50.00 per 1-hour session. Podiatrist every 6 weeks at $43.00. Dentistry as needed. Guestimate of $400 yearly. Paid companion typically averaging 5 hours per week at $15.00 per hour. Laundry cost is approximately $15.00/week. Hairdresser (typically weekly) is $30.00.

> Every 3-4 months a permanent wave costs $150.00, so average $40.00/week on hairdressing.

A general observation was that some things to do with physical conditions in the facility, such as temperature control, should be covered by the facility.

> Some things should be handled by the facility. For instance the matter of ht need for fans because of lack of air conditioning and for blackout curtains to help keep the room cool in summer and warm in winter.

Appendix I: Case Study # 2

DESCRIPTIVE INFORMATION:

The family caregiver is under sixty-five years old, retired, one of several caregivers and the daughter of the resident. She resides three kilometres from the facility and visits three to four times per week. The age of the female resident is ninety-two years. She has been a facility resident for thirty months, and resides in a semi-private room.

The resident's approximate income is $1,298 per month, and per diem is $28.10 which averages $855 per month. The additional charge for a semi-private room differential is $233 per month, for a total charge of $1,088 per month.

Physical limitations include left-side mobility problems as a result of a stroke; requires use of a wheelchair full-time; must use lift for transfer to bed and toilet; has some difficulty in swallowing. Cognitive limitations include short-term memory loss. The resident knows family but cannot follow the calendar for day and date.

DIARY EXPENDITURES:

Facility charges taken from resident comfort fund totalled $90.98 for the month of December 2004. Charges included $19.66 for outings ($4.00 for van transportation and $15.66 for meals); four hairdresser charges of $16.08 each; and a birthday gift purchase from the gift shop of $7.00. The monthly bill for Shaw Cable is $51.41. The two-week expense diary documented additional out-of-pocket expenditures. Transportation costs to the family member were $34.65 for the period; and cost of three loads of laundry at $5 per load was $15.00. An additional $19.76 was spent on toiletries, flowers and supper. In-facility dental clinic charge for cleaning and fluoride treatment was $97.30; and fee for doctor's signature on a required tax form was $40.00. A parking permit cost $10.00. These three items were deemed to be annual expenditures, so the monthly cost was calculated to be $12.28 for the three. An eye exam cost $79.00 and was the first in thirty months, therefore was prorated at $2.65 for a month. Podiatry costs $10 every three months, so was prorated at $3.33 per month. Extra out-of-pocket expenditures were calculated based on the above to be approximately $311.34 per month. **Combined with the per diem and room differential charge, total expenditures are roughly $1,399.04. Note that the resident's gross income is approximately $1,298 per month.**

AVERAGE EXPENDITURES, DECLINED EXPENDITURES AND HARDSHIP:

As in the first case study, the respondent indicated that two-week diary expense entries under represented expenditures for an average two-week period. Once again, the cost of periodic and or large purchases was mentioned as missing.

> Due to snowfall and then heavy rainfall, I did not visit as regularly or for as long as I did not bring mum home for dinner since New Year's Day. Now I'm back to a more regular schedule. I have not estimated cost of "Teabisk" cookies kept in mum's drawer, mugs for tea, bath gel, powder, room spray, shampoo, conditioner, setting lotion, deodorant, toothbrushes, perfume. **Cost of periodic large purchases is not included.** [Emphasis added.]

The respondent indicated that to date there are no items or services which would be a health benefit to the resident which are not purchased or accessed due to cost. This is interesting based on the fact that the resident's income in this case study was the lowest of the four in the study sample, and that itemized expenditures (including per diem and room differential charge) exceeded the resident's gross income.

The respondent indicated out-of-pocket costs were imposing a financial hardship on the resident, who continues to rely upon depleting her remaining assets to cover expenditures.

> Mum expected to leave some inheritance to her daughters, grandchildren and great grandchildren – nothing very significant, but something to show for her life (as she sees it.) **Her term deposits are gradually being cashed in, as her annuities, old age security, guaranteed income supplement, Canada Pension, GST rebate and interest are not enough to cover her expenses in residential care.** [Emphasis added.] A terrible way to treat seniors for their contribution during depression, war, recession, etc.

CAPITAL EXPENDITURES, ADDITIONAL SERVICES AND GENERAL COMMENTS:

Expenditures on large capital items do not occur on a regular basis, as needs vary and purchases are made as need arises. The cost associated with maintaining a specialized wheelchair was mentioned, although the original purchase was not itemized. The two major capital items mentioned were a wheelchair back, and room furnishings.

> A new wheelchair back was purchased in 2002. A storage drawer set and armoire had to be purchased for mum's clothes, as very limited space provided by facility – just night table and small closet. The furniture purchase was

> $570.00. As well a $20 fan had to be purchased because the facility has no air conditioning.

Additional services were also purchased for the resident. These included dental and denturist services, and eye examinations, and non-medical services such as signing disability forms for income-tax, and hairdressing.

> Until this year I took mum to the family dentist for teeth cleaning and adjustment of partial dentures. Recently we paid $97.30 for dental services in-facility. The dentistry clinic at the facility is more expensive than the family dentist. When I asked why, the response was "specialized geriatric car" as these patients are "more difficult." Yet the clinic at the facility is part of the UBC dentistry school, so space and overhead are covered by the facility, and the dentistry chairs were donated when the Chilliwack Army Base was closed down. An eye exam arranged by the facility cost $79.00. This was the first one in 30 months. A medical doctor charged $40 for her *signature* on the tax disability form needed for income tax filing. This cost is not covered by the medical services plan of BC. Haircuts and styling cost $50 every 3 months.

Mention was made of the purchase of specialized non-skid slippers recommended by the physician. "Special slippers were purchased for $110 in 2002 and replaced for $100 in 2004." Other respondents mentioned the cost of specialized clothing as well. Purchase of preferred nutritious snack foods and treats was also a common out-of-pocket expenditure.

> Mum does not like the facility food, so I often keep individual yogurts in the fridge for her through the summer. I also keep her night stand supplied with teabags and cookies.

This family member mentioned the importance of room decorations and activities to maintain a home-like atmosphere and aid in cognition.

> I decorate walls and door and display personal items to make the space more home-like and personal. also helps maker her aware of seasons. Decorate for Valentine's Day, St. Patrick's Day, Easter, Sprig, Summer, Thanksgiving, Halloween and Christmas. Purchased plants for patio gardening – mum was designated a large urn for gardening, but no plants were provided. Purchased windsocks and chimes for outside room window, but these were repeatedly vandalized or stolen, so now put them in trees in patio area off dining room.

Concern was expressed that staff does not have enough time to help her mother do more walking to maintain mobility, and that this is a potential out-of-pocket expenditure.

> I would like mum to do more walking, but I have not looked into the cost of this service, and now rehabilitation services are likely to be cut back before September 2005.

Appendix J: Case Study # 3

DESCRIPTIVE INFORMATION:

The family caregiver is under sixty-five years old, retired, one of several caregivers and the daughter of the resident. She resides fifteen kilometres from the facility and visits three to four times per week. The age of the male resident is eighty-eight years. He has been a facility resident for forty-eight months, and has a wife who still resides in the family home but requires assistance due to physical impairment.

The resident's approximate income is $3,333 per month, and per diem is $63.91 which averages $1,944 per month. There is no additional charge for a room differential.

The physical impairments of the resident are that he cannot walk or transfer; cannot feed or dress himself. He suffers hearing loss on the right side. Cognitive limitations include loss of language and some dementia. He has good comprehension, but cannot verbally communicate. He remembers the past well and understands what is happening around him.

DIARY EXPENDITURES:

Expenses from two-week diary totalled $598.00, and included twenty-two hours of paid caregiver time at $22 per hour; a facility van charge of $2.00; two family tickets to a special event dinner in the facility at $10 per ticket; two music therapy sessions at a cost of $40 per one-hour session; and a haircut for $12. As well the facility bills $40 monthly for podiatrist visits, $75 for dentistry, which was listed also noted as a *monthly* charge, and $20 in pharmacy charges for the one month period of December 2004. Total out-of-pocket costs for a one month period are estimated to be $1,430.67. Transportation costs to the family member were not documented in the diary, but conservatively calculated on only three visits per week (30 km per round trip) with no other transportation costs, this equates to another $175.50 per month in expenses (using $0.45/km to calculate mileage). **Out-of-pocket expenditures combined with the per diem charge equate to monthly expenditures of approximately $3,550.50. No capital expenses are included (e.g. wheelchair, cushions, etc.) Note that the resident's gross income is approximately $3,333 per month.**

AVERAGE EXPENDITURES, DECLINED EXPENDITURES AND HARDSHIP:

The respondent felt that the two-week expense diary costs were representative of an average two-week period, and commented that all bowel care, medical supplies, skin care, incontinence management, and nutritional supplements are supplied at the facility without extra charge. However, it must be noted that the pro-rated cost of large expenditure items such as wheelchairs are not captured by the two-week diary. Neither are costs such as specialized clothing purchases and capital items such as hip protectors. The respondent indicated that there are never occasions when items/services which would be a health benefit to the resident are not purchased or accessed due to cost.

> **Dad now needs a recliner wheelchair. cost will be about $5,000 to the family.** Dad responds very well to music therapy – one of his few activities – so family have arranged for one-on-one therapy one hour per week at a cost of $40 per hour. **Over the last 2 years, approximately $2,000 has been spent by the family on hip protectors and adaptive clothing (i.e. seamless pants for ease of dressing/undressing/toileting a wheelchair-bound person).** [Emphasis added.]

Out-of-pocket costs are imposing financial hardship on the family. This is a resident who still has a frail, elderly spouse residing with assistance outside of the facility in their family home.

> There has been a large reduction of savings over the last 4 years due to expenses that exceed net family income by over $2,000 per month. **The cost of accommodation and services per month for dad as identified above exceed his NET income by about $1,200 per month. His wife, who still lives at home and receives just the OAP needs an additional $1,500 per month or so to cover caregiver and cost of living expenses. "This means that about $2,700 per month is being drawn from savings (i.e. over $30,000 per year).** [Emphasis added.]

CAPITAL EXPENDITURES, ADDITIONAL SERVICES AND GENERAL COMMENTS:

The family incurs large capital expenditures (such as the specialized wheelchair mentioned above) approximately once every three years, but costs of these items will vary. Ongoing expenditures such as specialized clothing were also noted above. Out-of-pocket costs also include a paid caregiver, pharmacy charges, podiatry, dentistry, and haircuts.

> We incur the following additional costs: a care person to assist with exercise therapy and feeding 2 hours per day, Monday – Friday at a cost of $22.00 per hour; pharmacy costs of $20.00 per month; $55 podiatrist charge once each 6

weeks which works out to be approximately $40.00 per month; dentist once each month at $75.00; and haircuts at $12.00 once per month.

Appendix K: Case Study # 4

DESCRIPTIVE INFORMATION:

The family caregiver is over sixty-five years old, retired, the sole caregiver and the husband of the resident. He resides 5.5 kilometres from the facility and visits twice a day, seven days per week. The age of the female resident is seventy-seven years. She has been a facility resident for sixteen months, and resides in a semi-private room

The resident's approximate income is $1,500 per month, and the facility per diem is $32.85 which averages $999 per month. The additional charge for a semi-private room differential is $233 per month, for a total charge of $1,232 per month.

The physical impairments of the resident are that she is in a wheelchair full-time, and use of one arm and hand is compromised. She requires assistance with transfers, dressing, and toileting. Her cognitive limitation is dementia.

DIARY EXPENDITURES:

Expenses from two-week diary totalled $520.31 and included transportation costs of $308 (308 kilometres X $0.45/km mileage rate); hairdressing cost of $42.00; dry cleaning and alterations for $27.36; clothing for $28.48; toiletries for $24.95; fresh fruit for $6.00; flowers and candy for $83.52. **Total out-of-pocket costs for a one month period are estimated to be $1,127.34. Out-of-pocket expenditures combined with the per diem and room differential charges total monthly expenditures of approximately $2,359.34. No capital expenses are included (e.g. wheelchair, cushions, etc.) Note that the resident's gross income is approximately $1,500 per month.**

AVERAGE EXPENDITURES, DECLINED EXPENDITURES, AND HARDSHIP:

The respondent felt that two-week diary expenditures captured representative expenditures over an average two-week period. No capital expenditures were included in the diary. There are no occasions when items or services which would be a health benefit to the resident are not purchased or accessed due to cost. The respondent indicated that out-of-pocket

expenditures do not impose financial hardship in spite of the fact that out-of-pocket expenditures, per diems and room differential charges exceed the resident's gross income by over $800 per month.

CAPITAL EXPENDITURES, ADDITIONAL SERVICES AND GENERAL COMMENTS:

There was no response regarding the type, cost, or frequency of large capital purchases. Additional services paid for included dentistry, podiatry, and companion services.

> Dental care costs are approximately $300.00 per year. Podiatrist costs $80.00 per year. Companion services cost about $48.00 per month.

Appendix L: Facility Insurance Coverage Performance Scores

Score = (# items) x (amt. of coverage)
0 = no coverage, 1 = partial coverage, 2 = full coverage
No coverage means resident pays full cost of item or service; partial coverage means some residents pay, or residents pay some percentage of cost depending upon circumstances; full coverage indicates that the item or service is provided without charge to all residents.
Missing answers (indicated by n < 8 for cohort or n < 4 for each facility type) indicate "don't know" response from interviewee.

Item or Service Coverage Score	Cohort N (%)	For-Profit N (%)	Not-For-Profit N (%)	Comments	Items
Fruit Laxative (1 item, max score = 2)	(n=8)	(n=4)	(n=4)		
0 (no coverage)	**7 (87.5)**	**1 (25.0)**	**0 (0.0)**		
2 (full coverage)		**3 (75.0)**	**4 (100.0)**		
Bowel Care (3 items, max score=6)	(n=6)	**(n=3)**	(n=3)		**OTC laxatives, enemas, suppositories**
0 (no coverage)	**2 (33.3)**	**1 (33.3)**	**1(33.3)**		
2	**2 (33.3)**	**0 (0.0)**	**2 (66.7)**		
4	**1 (16.7)**	**1 (33.3)**	**0 (0.0)**		
6 (full coverage)	**1 (16.7)**	**1 (33.3)**	**0 (0.0)**		
Wound Care (5 items, max score=10)	(n=6)	**(n=4)**	(n=2)		**ostomy supplies, dressing change trays, dressings, compression support stockings, pressure ulcer treatments**
2					
3	**1 (16.7)**	**1 (25.0)**	**0 (0.0)**		
4	**1 (16.7)**	**0 (0.0)**	**1 (50.0)**		
7	**2 (33.3)**	**2 (50.0)**	**0 (0.0)**		
8	**1 (16.7)**	**0 (0.0)**	**1 (50.0)**		
	1 (16.7)	**1 (25.0)**	**0 (0.0)**		
Hip Protectors (1 item, max score = 2)	(n=7)	**(n=4)**	(n=3)	**no difference between facility types**	
0 (no coverage)	**7 (100.00)**	**4(100.0)**	**3 (100.00)**		
OTC Medications (5 items, max score=10)	(n=7)	**(n=3)**	(n=4)	**not-for-profit = less coverage**	**Imodium, Tylenol, Gravol, calcium, iron supplement**
0 (no coverage)					
3	**4 (57.1)**	**1 (33.3)**	**3 (75.0)**		
8	**2 (28.6)**	**1 (33.3)**	**1 (25.0)**		
	1 (14.3)	**1 (33.3)**	**0 (0.0)**		
Oxygen (1 item, max score=2)	(n=8)	**(n=4)**	(n=4)		
0 (no coverage)	**3 (37.5)**	**1 (25.0)**	**2 (50.0)**		
1	**1 (12.5)**	**1 (25.0)**	**0 (0.0)**		
2 (full coverage)	**4 (50.0)**	**2 (50.0)**	**2 (50.0)**		

Item or Service Coverage Score	Cohort N (%)	For-Profit N (%)	Not-For-Profit (N)	Comments	Items
Ambulance Transport (1 item, max score=2)	(n=8)	(n=4)	(n=4)	**no difference between facility types**	
0 (no coverage	**8 (100.0)**	**4 (100.0)**	**4 (100.0)**		
Other Transport (2 items, max score=4)	(n=8)	(n=4)	(n=4)	**no difference between facility types**	**taxi transport, other transport**
0 (no coverage)	**8 (100.0)**	**4 (100.0)**	**4 (100.0)**		
Rehydration Therapy (2 items, max score=4)	(n=5)	(n=4)	(n=1)		**hypodermoclysis tubing, hypodermoclysis fluids**
0 (no coverage)	**1 (20.0)**	**1 (25.0)**	**0 (0.0)**		
4 (full coverage)	**4 (80.0)**	**3 (75.0)**	**1 (100.0)**		
Glucose Monitoring Strips (1 item, max score=2)	(n=8)	(n=4)	(n=4)	**not-for-profit = less coverage**	
0 (no coverage)	**3 (37.5)**	**1 (25.0)**	**2 (50.0)**		
1	**1 (12.5)**	**0 (0.0)**	**1 (25.0)**		
2 (full coverage)	**4 (50.0)**	**3 (75.0)**	**1 (25.0)**		
Skin Care (4 items, max score=8)	(n=7)	(n=4)	(n=3)	**for-profit = less coverage**	**special mattresses, air mattresses, egg crate mattresses, roho cushions**
0 (no coverage)	**3 (42.9)**	**3 (75.0)**	**0 (0.0)**		
1	**1 (14.3)**	**0 (0.0)**	**1 (33.3)**		
4	**1 (14.3)**	**0 (0.0)**	**1 (33.3)**		
6	**1 (14.3)**	**0 (0.0)**	**1 (33.3)**		
8 (full coverage)	**1 (14.3)**	**1 (25.0)**	**0 (0.0)**		
Podiatry Services (1 item, max score=2)	(n=8)	(n=4)	(n=4)	**no difference between facility types**	
0 (no coverage)	**8 (100.0)**	**4 (100.0)**	**4 (100.0)**		
Mobility Aids (4 items, max score=8)	(n=8)	(n=4)	(n=4)	**no difference between facility types**	**wheelchair, walker, crutches, cane**
0 (no coverage)	**8 (100.0)**	**4 (100.0)**	**4 (100.0)**		
Transfer Aids (3 items, max score=6)	(n=6)	(n=3)	(n=3)		**floor to ceiling bar, bedside assist bars, raised toilet seat**
0 (no coverage)	**1 (16.7)**	**0 (0.0)**	**1 (33.3)**		
1	**1 (16.7)**	**1 (33.3)**	**0 (0.0)**		
4	**1 (16.7)**	**1 (33.3)**	**0 (0.0)**		
6 (full coverage)	**3 (50.0)**	**1 (33.3)**	**2 (66.7)**		
Bed Alarm (1 item, max score=2)	(n=7)	(n=4)	(n=3)		
0 (no coverage)	**3 (42.9)**	**1 (25.0)**	**2 (66.7)**		
2 (full coverage)	**4 (57.1)**	**3 (75.0)**	**1 (33.3)**		

Item or Service Coverage Score	Cohort N (%)	For-Profit N (%)	Not-For-Profit (N (%)	Comments	Items
Incontinence Management (7 items, max score=14) --- 10 11 12 14 (full coverage)	(n=6) --- 1 (16.7) 1 (16.7) 1 (16.7) 3 (50.0)	(n=3) --- 1 (33.3) 0 (0.0) 0 (0.0) 2 (66.7)	(n=3) --- 0 (0.0) 1 (33.3) 1 (33.3) 1 (33.3)		barrier cream, diapers, incontinence pads, condom drainage bags, urinary catheters, portable urinals, commode
Nutritional Supplements (1 item, max score=2) --- 0 (no coverage) 2 (full coverage)	(n=8) --- 2 (25.0) 6 (75.0)	(n=4) --- 1 (25.0) 3 (75.0)	(n=4) --- 1 (25.0) 3 (75.0)	no difference between facility types	
Recreation (2 items, max score=4) --- 0 (no coverage) 1 2 3 4 (full coverage)	(n=8) --- 1 (12.5) 1 (12.5) 3 (37.5) 2 (25.0) 1 (12.5)	(n=4) --- 1 (25.0) 0 (0.0) 2 (50.0) 1 (25.0) 0 (0.0)	(n=4) --- 0 (0.0) 1 (25.0) 1 (25.0) 1 (25.0) 1 (25.0)		outings, within-facility groups and activities
Companion Services (2 items, max score=4) --- 0 (no coverage) 2 (full coverage)	(n=8) --- 7 (87.5) 1 (12.5)	(n=4) --- 4 (100.0) 0 (0.0)	(n=4) --- 3 (75.0) 1 (25.0)		paid companion, escort services to doctors' offices
Extra Baths (1 item, max score=2) --- 0 (no coverage) 1 2 (full coverage)	(n=8) --- 2 (25.0) 1 (12.5) 5 (62.5)	(n=4) --- 2 (50.0) 0 (0.0) 2 (50.0)	(n=4) --- 0 (0.0) 1 (25.0) 3 (75.0)	for-profit = less coverage	

Appendix M: Changes in Coverage from 2002 to Present

Coverage Changes Since 2002?	Cohort N (%)	For-Profit N (%)	Not-For-Profit N (%)	Comments	Items
Fruit Laxative (1 item)	(n=7)	(n=3)	(n=4)		
Yes	**2 (28.6)**	**2 (66.7)**	**0 (0.0)**		
No	**5 (71.4)**	**1 (33.3)**	**4 (100.0)**		
Bowel Care (3 items)	(n=6)	(n=2)	(n=4)		**OTC laxatives, enemas, suppositories**
Yes	**2 (33.3)**	**1 (50.0)**	**1 (25.0)**		
No	**4 (66.7)**	**1 (50.0)**	**3 (75.0)**		
Wound Care (5 items)	(n=5)	(n=3)	(n=2)		**ostomy supplies, dressing change trays, dressings, compression support stockings, pressure ulcer treatments**
Yes	**2 (40.0)**	**2 (66.7)**	**0 (0.0)**		
No	**3 (60.0)**	**1 (33.3)**	**2 (100.0)**		
Hip Protectors (1 item)	(n=4)	(n=2)	(n=2)	**no difference between facility types**	
Yes	**0 (0.0)**	**0 (0.0)**	**0 (0.0)**		
No	**4 (100.0)**	**2 (100.0)**	**2 (100.0)**		
OTC Medications (5 items)	**(n=5)**	(n=2)	(n=3)	**no difference between facility types**	**Imodium, Tylenol, Gravol, calcium, iron supplement**
Yes					
No	**0 (0.0)**	**0 (0.0)**	**0 (0.0)**		
	5 (100.0)	**2 (100.0)**	**3 (100.0)**		
Oxygen (1 item)	(n=4)	(n=1)	(n=3)		
Yes	**0 (0.0)**	**0 (0.0)**	**0 (0.0)**	**no difference between facility types**	
No	**4 (100.0)**	**1 (100.0)**	**3 (100.0)**		
Ambulance Transport (1 item)	(n=5)	(n=1)	(n=4)	**no difference between facility types**	
Yes	**0 (0.0)**	**0 (0.0)**	**0 (0.0)**		
No	**5 (100.0)**	**1 (100.0)**	**4 (100.0)**		
Other Transport (1 item)	(n=5)	(n=1)	(n=4)		
Yes	**0 (0.0)**	**0 (0.0)**	**0 (0.0)**	**no difference between facility types**	**taxi transport, other transport**
No	**5 (100.0)**	**1 (100.0)**	**4 (100.0)**		
Rehydration Therapy (2 items)	(n=4)	(n=3)	(n=1)	**no difference between facility types**	**hypodermoclysis tubing. hypodermoclysis fluids**
Yes	**0 (0.0)**	**0 (0.0)**	**0 (0.0)**		
No	**4 (100.0)**	**3 (100.0)**	**1 (100.0)**		
Glucose Monitoring Strips (1 item)	(n=5)	(n=4)	(n=1)		
Yes	**2 (40.0)**	**2 (50.0)**	**0 (0.0)**		
No	**3 (60.0)**	**2 (50.0)**	**1 (100.0)**		

Coverage Changes Since 2002?	Cohort N (%)	For-Profit N (%)	Not-For-Profit N (%)	Comments	Items
Skin Care (4 items)	(n=4)	(n=2)	(n=2)		
Yes	2 (50.0)	1 (50.0)	1 (50.0)		special mattresses, air mattresses, egg crate mattresses, roho cushions
No	2 (50.0)	1 (50.0)	1 (50.0)		
Podiatry Services (1 item)	(n=4)	(n=1)	(n=3)		
Yes	1 (25.0)	0 (0.0)	1 (33.3)		
No	3 (75.0)	1 (100.0)	2 (66.7)		
Mobility Aids (4 items)	(n=4)	(n=1)	(n=3)		wheelchair, walker, crutches, cane
Yes	0 (0.0)	0 (0.0)	0 (0.0)		
No	4 (100.0)	1 (100.0)	3 (100.0)		
Transfer Aids (3 items)	(n=3)	(n=1)	(n=2)		floor to ceiling bar, bedside assist bars, raised toilet seat
Yes	0 (0.0)	0 (0.0)	0 (0.0)		
No	3 (100.0)	1 (100.0)	2 (100.0)		
Bed Alarm (1 item)	(n=4)	(n=1)	(n=3)		
Yes	0 (0.0)	0 (0.0)	0 (0.0)		
No	4 (100.0)	1 (100.0)	3 (100.0)		
Incontinence Management (7 items)	(n=5)	(n=2)	(n=3)		barrier cream, diapers, incontinence pads, condom drainage bags, urinary catheters, portable urinals, commode
Yes	4 (80.0)	2 (100.0)	2 (66.7)		
No	1 (20.0)	0 (0.0)	1 (33.3)		
Nutritional Supplements (1 item)	(n=4)	(n=0)	(n=4)		
Yes	0 (0.0)		0 (0.0)		
No	4 (100.0)		4 (100.0)		
Recreation (2 items)	(n=5)	(n=3)	(n=2)		outings, within-facility groups and activities
Yes	3 (60.0)	1 (33.3)	2 (100.0)		
No	2 (40.0)	2 (66.7)	0 (0.0)		
Companion Services (2 items)	(n=5)	(n=2)	(n=3)		paid companion, escort services to doctors' offices
Yes	1 (20.0)	0 (0.0)	1 (33.3)		
No	4 (80.0)	2 (100.0)	2 (66.7)		
Extra Baths (1 item)	(n=8)	(n=4)	(n=4)		
Yes	3 (37.5)	2 (50.0)	1 (25.0)		
No	5 (62.5)	2 (50.0)	3 (75.0)		

Appendix N: Summaries of Key Informant Interviews

N-1: Karen Archibald, Manager, Information and Policy, home and Community Care Division, BC Ministry of Health Services

- Chairs "Optional Goods and Services Working Group" for residential care services. Group drafted a revenue generation policy outlining what must be included in per diems – not yet public information. Group's work and Draft Policy didn't address the pharmacy issue which Karen describes as "huge and difficult," and says would take another 3 years of work.
- Policy addresses supplies and equipment as well as room differentials, which she described as a "big issue." Facilities built after 1990 have single rooms only under multi-level care guidelines, so won't be an issue in newer facilities. Currently OAS/GOS recipients aren't charged room differentials and cannot request upgraded rooms (i.e. semiprivate or private). Current policy regarding maximum room differentials does not apply to extended care hospitals under the Hospital Act – they can charge whatever they want, and some have charged as much as $25/day. They stand to lose a substantial amount of money if practice disallowed or if new facilities have only single rooms. This must be looked at if all facilities to be brought under the new Community Care and Assisted Living Act under Section 12. There is a project under way contracted to a private consulting firm to review implications and make recommendations for implementation.
- "Plan B" is the pharmacy plan for continuing care facilities under the new Act. private hospitals are also on "Plan B". Facilities use a community pharmacy which bills Pharmacare a certain amount per bed – a capitation fee. RESIDENTS SHOULD NOT BE PAYING ANYTHING FOR PRESCRIPTION MEDICATION WHICH IS ON THE PROVINCIAL FORMULARY. There is generally co-payment for over-the-counter medications.
- Hospital Act facilities are not under "Plan B". Prescriptions and usually over-the-counter drugs are fully covered in Hospital facilities just as they are for acute care patients.
- Current provincial policy states that ostomy supplies, diabetic strips, incontinence supplies, nutritional supplements and so forth MUST BE PROVIDED AT NO EXTRA CHARGE to facility residents.
- Government currently reviewing services de-listed in 2002, such as physiotherapy, occupational therapy, podiatry, chiropractic and massage. Ministry may, in future, require these services plus social work to be fully covered and provided without charge in all facilities.
- Spring of 2005 Ministry is moving away from current care level classification system.

N-2: Linda Thomas, Director, Contracted Residential Care and Assisted Living Facilities, Vancouver Coastal Health

- Linda confirms there is a problem with interpretation of the Home and Community Care Policy Manual which serves as a service provider handbook. Describes facilities' interpretations and policies regarding extra charges as, "all over the map," and variability amongst facilities as "huge."
- Ministry of Health Services has initiated process to examine chargeable items and services in an attempt to bring standardization. Feels this is a provincial, not a Vancouver Coastal Health problem, and needs to be dealt with province-wide. VCH will not take lead role and is hesitant to gather information until province determines what should be done.
- Confirms that low-income residents receiving OAS/GIS pay 85% of income for basic room, board and care, plus out-of-pocket expenses. Out-of-pocket expenses are lower in facilities regulated under the Hospital Act, because items like over-the-counter medications and some therapies are covered.
- Not sure the variability in out-of-pocket charges is creating hardship for many residents, but feels charges should be standardized for reasonableness and fairness. Not fair that choice of where resident is placed due to bed availability results in different charges for similar items and services. (No choice in initial placement, but transfers are allowed and are relatively common.)

N-3: Linda Rose, Director, Vancouver Coastal health Directly-Operated Facilities

- At the end of January, 2005, there will be new performance indicators which will be included in contracts with facilities. The individual contracts are not public, but the performance standards will be.
- BC Ministry of Health Services is currently attempting to collect out-of-pocket billing information for Vancouver Coastal Health Facilities.
- VCH and the Ministry only check on expenditures from resident "comfort funds" if there is an audit or a specific complaint from a resident or family member regarding what they think is an unreasonable expense item. There is no standard reporting of billings charged to residents' personal accounts.
- Prescription medications for residents of facilities under the Hospital Act are treated like medications for acute care patients and are provided without charge. Facilities falling under Hospital Act 2 treat cost of prescription medication as they would be treated for people in the community, there is co-payment required.
- Confirms that she is aware there is still some inconsistence regarding charges for items like ostomy supplies and diabetic (glucose monitoring) strips. Interpretations of items which are supplied free of charge to residents vary by facility.
- The new block funding formula will have rehabilitation and some social work cost built in, although the block nature of funding allows facilities to choose to put money into whatever services they prioritize; they could, for example put the added money into nursing instead.

- Client per diems range from $28/day to $65/day on a sliding scale based on income. Per diems are inflation indexed. If resident is forced to sell/cash in an asset (for example to purchase a wheelchair), this might result in increased income for the year, and an increase in the per diem the following period.
- Faith-based and culturally-based facilities have more active auxiliaries than other types, and can raise more money and provide more volunteer time to residents. They are able to pick up more individual costs because of fund-raising and volunteer advantage.
- Provincial policy is that incontinence supplies are covered in all facilities.
- Tube feeding solutions are not paid for by residents in any facility.
- Questionable areas are Pharmacare-related.
- Known variability in charges for: ostomy supplies; diabetic strips, cable TV, recreational activities, room differentials.
- Current average length of staying residential care is only 18 months. People are placed very late in their lives and spend very short time in residential care before dying.
- The initiative to consolidate all long-term care facilities under the new Community Care and Assisted Living Act has been under way for 3 years, and may not be completed any time soon.

N-4: Nancy Rigg, Executive Director, Community Care Network, Regional Office, Vancouver Coastal Health

- Nancy Describes changes (phased in throughout 2002 – 2004) in eligibility criteria and service delivery for home support as a "huge change." Clients were reassessed and had hours changed. Case managers have very high caseloads. Many clients at the lower acuity level end of the spectrum of needs had home support hours cut.
- New system for assessing eligibility for residential care phases out system used since 1975, and categories such as Extended Care and Intermediate Care Levels 1, 2, and 3 are no longer used. More restrictive criteria eliminated eligibility for clients previously designated IC1 and IC2. New system is inter Rai system of tools, based on functional assessment level.
- All new residents classified as "complex care." Generally exhibit dementia or significant cognitive impairment.
- VCH currently has approximately 5,000 long-term care beds following recent closure of approximately 400 beds.
- Old priority lists were managed on chronological basis –now needs based; therefore people generally get residential care bed placements when they need them.

- Transitional care beds in operation for last 2 years assist people to move back into their own homes after acute episodes such as strokes, falls, surgeries, or other hospital admissions.
- Approximately 7,000 clients receive home support services. This does not count those purchasing their own private home support services.
- The split is approximately 50/50 in terms of residential care beds and community clients – approximately 5,000 of each at any given point in time. People transition into and out of community care, but stay in residential care, so more people over time use community services, but at a *point in time* the number is relatively constant at 5,000, just as it is for residential care beds.

N-5: Ed Helfrich, Executive Director, BC Care Association

- Ed is a member of the Ministry of Health "Chargeable Extras Committee" comprised of health authority and provider representatives.
- Committee has been working for 8 months gathering data regarding extra charges for items, serves, and room differentials. Hopes within 3 to 4months to have recommendation for Ministry regarding policy on room differentials and any remaining anomalies/inconsistencies round extra charges.
- Does not feel extra charges constitute a big problem – sys payments for over-the-counter drugs and supplies in general are quite minimal.
- Agrees that specialized wheelchairs and equipment are costly, but thinks few elderly residents require these items.
- Due to rising acuity levels in facilities, feels extra charges for items like cable, phone, newspapers, activities and so forth are less of an issue, as many residents can't take advantage of these in any event.
- Considers room differential charges most significant and contentious item, constituting a relatively large amount of money. Room differentials can be up to $9/day, for a total of $270/month. No new facilities are approved for room differentials, so there are newer, nicer room s which are provided without room differentials in some facilities, and less-desirable rooms in older facilities for which differentials still apply. This is part of current review process.
- Prescription medication covered in hospital-designated facilities and community and long-term care facilities under two different mechanisms – one under the Hospital Act and one under Pharmacare. Over-the-counter medications are paid by the client in non-hospital designated facilities.
- Implementing Section 12 of the Community Care and Assisted Living Act to bring all facilities under one act is a political decision which has financial implications. One is the difference in application of GST. This is particularly significant in terms of capital expenditures –not so much with operating expenses since these are mostly staffing, which is not subject to GST. There are ongoing discussions with the federal government regarding application of the GST under the new Act to minimize the negative financial impact of bringing all facilities under the new Act.

- Confirms that residents pay 85% of OAS/GIS for per diems, which leaves a maximum of $100 - $150 for all other expenses.
- Previously facilities charged for incontinence supplies –no longer. Diabetic (glucose monitoring) strips are still a grey area.
- Feels facilities will be hesitant to provide information regarding billings from comfort funds or trust accounts. Items like cable and phone charges (if not separated out) could skew numbers. Suggests asking public trustee for information.

Appendix O: BC Ministry of Health Services Residential Care Admission Criteria

Clients can only be approved for admission to residential care when all of the following conditions are met:

- client is assessed as complex care.
- client has an urgent need for residential care and will accept the first available and appropriate bed. Placing a client's name on a wait list in anticipation of need at some future time is not permitted.
- if the client is receiving convalescent care, whether in hospital or as a short term admission to residential care, the client's condition has been determined medically and functionally stable.
- it has been determined and documented that:
    - the client needs 24 hour supervision and continuous professional care, and the client's care needs cannot be met with available community resources;
    - the client's medical causes of disability and dependency which may be remedial have been investigated and treated;
    - the client's condition is medically and functionally stable;
    - the client's degree of risk is not manageable within available community resources and services;
    - the caregiver is living with unacceptable risk to their well-being.
- the client has agreed to accept admission into the facility, and to occupy the bed within 48 hours of being advised of the availability of the bed, unless previous arrangements were made with the health authority.
- the client has been advised of the applicable client rate, room differentials and permissible facility charges, and has agreed to pay all applicable costs.

Appendix P: Case Study Expense Diary and Questionnaire

DEMOGRAPHIC INFORMATION

1. Your Name:_____

2. Are you over 65 years of age? _____yes _____no

3. Your Work Status (i.e. working full/part-time, retired, etc.) _____

4. Are you the: ____sole family caregiver? ____one of several family caregivers?

5. Relationship to Long-Term Care Resident (i.e. spouse, son-in-law, daughter, etc.)
_____

6. Distance from Your Residence to the Facility: _____

7. Approximate Frequency of Your Visits to the Facility: _____

8. Name of Intermediate Care Facility: _____

9. Age of Resident:_____ 10. Gender of Resident _____

11. Length of Time Resident has been in a Long-Term Care Facility: _____

12. Physical Limitations of Resident (i.e. mobility, hearing, vision):
_____
_____
_____

13. Cognitive Limitations of Resident (i.e. short and long-term memory, dementia):
_____
_____
_____

14. Chronic Conditions/Diagnoses of Resident (i.e. incontinence, arthritis, diabetes, heart disease etc.):
_____
_____
_____

15. Monthly Charge to Resident for basic facility room/board/care: _____

16. Room Differential (If charged additional daily rate for semi-private, private, or otherwise superior to standard facility room): _____

17. Approximate Gross Income of Resident: _____

ITEMS AND SERVICES BILLED TO RESIDENT BY FACILITY FOR MOST RECENT ONE-MONTH BILLING PERIOD

If possible, please attach a copy of the itemized December 2004 invoice from facility showing items paid for from resident's comfort funds, and any other December 2004 invoices or direct billings from the facility. Otherwise, please itemize these costs below.

ITEMS & SERVICES Billed to Resident for the one-month period. (Refer to sample list attached to Caregiver Cover Letter for examples of items and services.)

Item/Service	Quantity	Total Cost

SAMPLE TWO-WEEK EXPENSE DIARY PAGE

This page provides an example of how to fill in diary pages each day for the two-week period.

Tuesday, Week One

Date: January 11, 2005

Item/Service Paid For	Quantity	Cost
Prescription drugs	*2 prescriptions*	*$20.00*
bed guard rail	*1*	*$75.00*
music therapy	*1 hour facility activity*	*$12.00*
denture supplies	*1 month supply*	*$15.00*
Transportation	**Mode**	**Cost**
Round trip visit to facility	*20 kms by private car*	*$9.00*
Drive resident to specialist	*30 kms by private car* *plus **parking***	*$14.50* *$ 8.00*
Round trip to specialist	*Taxi*	*$42.00*

Please complete the following pages daily for the two-week period.

TWO-WEEK EXPENSE DIARY

Sunday, Week One

Date: _____

Item/Service Paid For	Quantity	Cost
Transportation	**Mode**	**Cost (including parking)**

Monday, Week One

Date: _____

Item/Service Paid For	Quantity	Cost
Transportation	**Mode**	**Cost (including parking)**

Tuesday, Week One

Date: _____

Item/Service Paid For	Quantity	Cost
Transportation	**Mode**	**Cost (including parking)**

Wednesday, Week One
Date: _____

Item/Service Paid For	Quantity	Cost
Transportation	**Mode**	**Cost (including parking)**

Thursday, Week One
Date: _____

Item/Service Paid For	Quantity	Cost
Transportation	**Mode**	**Cost (including parking)**

Friday, Week One
Date: _____

Item/Service Paid For	Quantity	Cost
Transportation	Mode	Cost (including parking)

Saturday, Week One
Date: _____

Item/Service Paid For	Quantity	Cost
Transportation	**Mode**	**Cost (including parking)**

Sunday, Week Two
Date: _____

Item/Service Paid For	Quantity	Cost
Transportation	**Mode**	**Cost (including parking)**

Monday, Week Two
Date: _____

Item/Service Paid For	Quantity	Cost
Transportation	**Mode**	**Cost (including parking)**

Tuesday, Week Two
Date: ______________

Item/Service Paid For	Quantity	Cost

Transportation	Mode	Cost (including parking)

Wednesday, Week Two
Date:

Item/Service Paid For	Quantity	Cost

Transportation	Mode	Cost (including parking)

Thursday, Week Two
Date: ______________

Item/Service Paid For	Quantity	Cost

Transportation	Mode	Cost (including parking)

Friday, Week Two
Date: _____

Item/Service Paid For	Quantity	Cost
Transportation	**Mode**	**Cost (including parking)**

Saturday, Week Two
Date: _____

Item/Service Paid For	Quantity	Cost
Transportation	**Mode**	**Cost (including parking)**

On the following page please comment on whether or not the expenses itemized over the two-week period in the diary were typical and represent roughly "average" types of expenditures and amounts and comment on any items/services which were not purchased because of cost.

Please Mark the Most Appropriate Answers Below:

1. The types and amounts of expenditures itemized over the two-week diary period:
_____capture representative expenditures over an average two-week period
_____under represent average two-week expenditures
_____over represent average two-week expenditures

Comments:

_____
_____
_____
_____
_____
_____
_____

2. There are items/services which would be a health benefit the resident which are not purchased or accessed due to cost:
_____never
_____sometimes
_____often

Comments:

_____
_____
_____
_____
_____
_____
_____

3. The out-of-pocket costs of residential care:
_____impose financial hardship on the resident
_____impose financial hardship on the family
_____do not impose financial hardship

Comments:

_____
_____
_____
_____
_____
_____
_____

References

Alexander, T. (2002). The history and evolution of long-term care in Canada. In M. Stevenson & E. Sawyer. (Eds.), *Continuing the care: The issues and challenges for long-term care* (pp. 1-56). Ottawa. CHA.

Armstrong, W. (2002) Eldercare – on the auction block: Alberta families pay the price. Alberta Edmonton. Alberta Chapter CAC.

BC Association of Speech/Language Pathologists and Audiologists *Buying hearing aids: Frequently asked questions.* BCASLPA Website. http://www.bcaslpa.bc.ca/aifFAQ.htm

BC Ministry of Health and Ministry Responsible for Seniors. (1999). *Model standards for continuing care and extended care services.* Victoria. Queen's Printer. Retrieved from http://www.healthservices.gov.bc.ca/cpa/publications/modelstandardsofcare.pdf

BC Ministry of Health and Ministry Responsible for Seniors (2000) *Strategic directions for continuing care renewal.* Victoria. Queen's printer. Retrieved from http://www.hlth.gov.bc.ca/cpa/publications/sd_ccrenewal.pdf

BC Ministry of Health and Ministry Responsible for Seniors. (2001). *BC palliative care benefits program: Program description.* Victoria. Queen's Printer. Retrieved from http://www.healthservices.gov.bc.ca/cpa/publications/palliativebenefits.pdf

BC Ministry of Health and Ministry Responsible for Seniors. (2001). *Choosing a care facility of home: A guide to choosing a licensed residential care facility or residential care home.* Victoria. Queen's Printer. Retrieved from http://www.healthservices.gov.bc.ca/ccf/adult/com031.pdf

BC ministry of Health Services (2002) *BC's new residential care access policy.* Retrieved December 20, 2004 from http://www.healthservices.gov.bc.ca/hcc/pdf/residentialpolicy.pdf

BC Ministry of Health Services. (2002). *The facts about residential care.* Retrieved December 20, 2004 from http://www.healthservices.gov.bc.ca/hcc/pdf/factsrescare.pdf

BC Ministry of Health Services. (2003)/ *BC PharmaCare" Your new fair PharmaCare program: Fair care for everyone.* Retrieved December 20, 2004 from http://www.healthservices.gov.bc.ca/epa/publictions/fair_brochure.pdf

BC Ministry of Health Services. (2004). *Health care today and tomorrow.* Retrieved December 20, 2004 from http://www.healthservices.gov.bc.ca/bchealthcare/

BC Ministry of Health Services (2004) *Home and community care fees.* Retrieved February 16, 2005 from: http://www.healthservices.gov.bc.ca/hcc/fees.html

BC Ministry of Health Services. (2004). *Home and community care policy manual.* Policy 6.B.3. Standardized Assessment. Received via e-mail from Ministry (not accessible without password on internet).

BC Ministry of Health Services. (2004). *A profile of seniors in British Columbia.* Victoria. Queen's Printer. Retrieved from http://www.healthservices.gov.bc.ca/cpa/pblications/profile_of_seniors.pdf

BC Ministry of Health Services. (2004). *Residential facility assessment instrument for residential care facilities.* Victoria. Queen's Printer. Retrieved from http://www.healthservices.gov.bc.ca/ccf/adult/instrume/index.html

BC Ministry of Human Resources (2005) *BC Employment and Assistance Manual.* Victoria. Queen's Printer. Retrieved February 16 from : http://www.mhr.gov.bc.ca/publicat/Vol1/part7/7-15.htm

Canadian Centre for Policy Alternatives – BC Office, British Columbia Government and Service Employees' Union, British Columbia Nurses' Union and Hospital Employees' Union. (2000). *Without foundation: How Medicare is undermined by gaps and privatization in Community and Continuing Care.* Vancouver: Retrieved October 20, 2004 from http://www.policyalternatives.ca/bc/withoutfoundation.htm.

Cohen, M. (2003) *A dramatic reversal of policy on long-term care* In Health Care Restructuring in BC, A CCPA Policy Brief. Vancouver. CCPA.

Community Care and Assisted Living Act. [SBC 2002] Chapter 75. http://www.qp.gov.bc.ca/statreg/stat/C/02075_01.htm

Community Care and Assisted Living Act Adult Care Regulations. [OC # 2539/80] [Regulation 536/80] http://www.healthservices.gov.bc.ca/hcc/residential.html

Community Care and Assisted Living Regulations. [OC # 476/04]. [Regulation 217]. http://www.qp.gov.bc.ca/statreg/reg/C/CommuCareAssisted/217_2004 htm.

Crawford, C. (2003). *The assisted living industry in British Columbia.* Vancouver: Simon Fraser University.

Doran, E, Robertson, J., Rolfe, I., and Henry, D. (2004) Patient co-payment and use of prescription medicines.*Aust N Z. J Public Health* 28(1): 62-7. Retrieved January 7, 2004 from MEDLINE.

Fast, J., Keating, N., Oakes, L., and Williamson, D. (1997) *Conceptualizing and operationalizing the hidden costs of informal elder care: Final technical report to the national health research development program NHRDP Project no 6609-1963-55.* Ottawa. Health Canada.

Gee, E. (2000). Population and Politics: Voodoo demography, population aging, and Canadian social policy. In E. Gee & G. Gutman. (Eds.). *The overselling of population aging: Apocalyptic demography, intergenerational challenges, and social policy.* (pp. 5-25). Don Mills. Oxford University Press.

Gee, E. & Gutman, G. (Eds.). (2000). *The overselling of population aging: Apocalyptic demography, intergenerational challenges, and social policy.* Don Mills. Oxford University Press.

Goldman et al. (2004) Pharmacy benefits and use of drugs by the chronically ill. *JAMA* 291(19), 2344-2350. Retrieved January 7, 2004 from MEDLINE.

Goren, S. and Baird, A. (2000) Access to dental care for individuals with special needs. *Ontario Dentist.* May 2000: 15-20. Retrieved January 20, 2005 from http://www.oda.on.ca/Accesst_Goren_OD0500.pdf

Havens, B. (2002). Users of long-term continuing care. In M. Stevenson & E. Sawyer. (Eds.), *Continuing the care: The issues and challenges for long-term care.* (pp. 87-108). Ottawa: CHA.

Hollander, M., Chappell, N., Havens, B., McWilliams, C., and Miller J. (2002) *Substudy 5 of the national evaluation of the cost-effectiveness of home care: Study of the costs and outcomes of home cre and residential long term care services.* Victoria. Holander Analytical Service Ltd. Retrieved August 10, 2004 from http://www.homecarestudy.com/reports/full-text/substudy-05-final_report. pdf

Hospital Act. [RSBC 1996] Chapter 200. http://www.qp.gov.bc.ca/statreg/stat/H/96200_01.htm

Hospital Act Regulations. [OC 414/97],[BC Reg 121/97 including amendments up to BC Reg 496/2003.] http://www.qp.gov.bc.ca/statreg/reg/H/121_97.htm

Hospital Employees Union. (2002). *Profits distort priorities: Study of long-term care facilities in British Columbia.* Vancouver.

Jensen, J. (2004). *Catching up to reality: Building the case of a new social model. CPRN Social Architecture papers Research Report F| 35, Family Network.* Ottawa. CPRN

Keefe, J. and Fancey P. (1998) *Financial compensation versus community supports: An analysis of the effects on caregivers and care receivers: Final report.* Ottawa. Health Canada.

Kozyrskyj, A., Mustard, C., Cheang, M., and Simons, F. (2001). Income Based Drug Benefit Policy: Impact on receipt of inhaled corticosteroids prescriptions by Manitoba children with asthma. CMAJ 165(7) 897-902.Retrieved August 4, 2004 from MEDLINE.

Kozyrskyj, A., Mustard, C., Simons, F. (2001). Socioeconomic status, drug insurance benefits and new prescriptions for inhaled corticosteroids in school children with asthma. *Arch Pediatr Adolesc Med.* 155, 1219-1224. Retrieved August 4, 2004 from MEDLINE.

MacLean, M. & Greenwood Klein, J. (2002). Accessibility to long-term care: The myth versus the reality. In M. Stevenson & E. Sawyer. (Eds.), *Continuing the care: The issues and challenges for long-term care.* (pp. 71-86). Ottawa: CHA.

Office of the Provincial Health Officer, BC Ministry of Health Planning. (2004). *Prevention of falls and injuries among the elderly: A special report from the office of the provincial health officer.* Victoria. Queen's printer. Retrieved from http://www.healthservices.gov.bc.ca/pho/pdf/falls.pdf

Ontario Health Coalition (2002) *Ownership matters: Lessons from Ontario's long term care facilities.* Toronto. OHC. Retrieved December 20, 2004 from http://www.web.net/~ohc/docs/may2702.htm

Patterson, C. (1994) Prevention of hearing impairment and disability in the elderly. In *Canadian task force on the periodic health examination. Canadian guide to clinical preventive health care.* (pp. 954-63). Ottawa. Health Canada

Pitters, S. (2002). Long-term care facilities. In M. Stevenson & E. Sawyer. (Eds.). *Continuing the care: The issues and challenges for long-term care.* (pp. 163-202). Ottawa. CHA.

Poizner, S.(2004) A career to smile about. Special to *The Toronto Sun.* Retrieved April 5, 2005 from http://www.canoe.ca/CareerConnectionNews/040331_health.html

Robson, W. (2002). *Saving for Health: Prefunding health care for an Older Canada.* The health papers. No. 170. Toronto. C.D. Howe Institute December 20, 2004. http://www.cdhowe.org/pdf/commentary_170.pdf

Soumerai, S., McLaughlin, T., Ross-Degnan, D., Casteris, C., and Bollini, P. (1994) Effects of limiting Medicaid drug-reimbursement benefits on the use of psychotropic agents and acute mental health services by patients with schizophrenia. *N. Engl. J. Med.*331(10), 650-655. Retrieved August 15, 2004 from Massachusetts Medical Society Online Publications.

Soumerai, S. Ross-Degnan, D., Avorn, J., McLaughlin, T., and Choodnovskiy, I. (1991) Effects of Medicaid drug payment limits on admission to hospitals and nursing homes. *N. Engl. J. Med.* 325(15),1072-1077., Retrieved August 15, 2004 from http://www.google/ca/search?h/=en&q=%22Effects+of+limiting+Medicaid=drug-reimbursement+benefits+on+the+use+of+psychotropic+agents+and+acute+mental+health+services+by+patients+with+schizophernia%22&spell=1

Stephenson, M. & Sawyer, E. (Eds.). (2002). *Continuing the care: The issues and challenges for long-term care. Revised edition.* Ottawa: CHA

Tamblyn et al. (2001, January 24/31). Adverse events associated with prescription drug cost sharing among poor and elderly persons. *JAMA* 285(4) 421-429. Retrieved August 15, 2004 from http://jama.ama-assn.org/content/vol285/issue4/indexdtl

Tamblyn, R. (2001, Autumn) The impact of pharmacotherapy: A case study. *Can. J Clin Pharmacol.* 8(Supplement A), 39A-44A. Retrieved August 15, 2004 from MEDLINE.

Urban Futures Institute (1998). *Healthy Choices: Demographics and Health Spending in Canada, 1980 to 2035.* Vancouver. Abstract from http://www.urbanfutures.com/Institute/abstracts/report26.htm

Urban Futures Institute. (1999) *Without Care? Demographics and health spending in British Columbia, 1999 to 2040. Urban Futures Institute Report # 37.* Vancouver, BC: Retrieved January 2, 2005 http:// www.urbanfutures.com/Institute/abstracts/report37.htm.

Vancouver Island Health Authority. (Spring 2004). *Care: Child and adult residential care licensing.* Victoria. Retrieved October 10, 2004 from http://viha.ca/mho/Licensing/pdf/ul-care9,pdf