APPENDIX I

Figure 1: A Model for Understanding Private Companion Use
APPENDIX 2  Information Sheet and Study Questionnaire

Figure 2: An Overview of Key Variables included in the Questionnaire
Information Letter & Consent Form for the Study Questionnaire

"To Hire or Not to Hire a Private Companion: Factors Contributing to the Decision"

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Funding: SSHRC Doctoral Award, Ontario Graduate Scholarship / Lupina Doctoral Fellowship

Study Information:

- I would like to invite you to participate in this study of families with and without private companions.
- In order to decide whether you wish to participate in this research study, it is important that you read and understand what the study entails.

Study Purpose:

- The purpose of this study is twofold: 1) to understand the factors that contribute to the families’ decision to either hire or not to hire a private companion for their relative living in a nursing home; 2) to understand the role private companions serve for families who hire them.

Study Involvement:

- Your participation in this study involves completing the attached questionnaire, which will take about 20 minutes.
- You will also be asked if you are interested in participating in a face-to-face interview at a later date with the researcher. If you choose to participate, you will be asked about your experiences as a family member with a relative in a nursing home, and your views on private companion services.
- All data collection for this study will be conducted between August 2007 and December 2007.
- Your participation in this study is completely voluntary.
- You may choose to not answer all or some of the study questions and you may withdraw at any time.
- Your decision to participate, decline to participate, or withdraw from the study at any time, will not affect access to any services you, your older relative, or the private companion receive.
- There is no financial compensation for participating in this study.

Confidentiality:

- Your relative, the private companion, or the staff at the nursing home, will not have access to the responses you have shared, and they will not know whether or not you participated in this study.
- The information you provide in the questionnaire will not be matched or linked to any other identifying information.
- All questionnaires will be kept in a locked filing cabinet that is accessible only to the researcher. All data will be kept in a password-protected computer file. All questionnaires will be destroyed after the completion of the study.
- All data will be reported in group form and used for scholarly purposes. I would be pleased to provide you with a summary of the results of this study upon your request.
Risks and Benefits:

- There are no risks related to the completion of this questionnaire. However, you may wish to discuss the material further with the researcher.

- There are no direct benefits to you, your family or the private companion, for participating in this study. However, some family members may find discussing their experiences about having a relative in a nursing home helpful.

- Your participation in this study will provide valuable information about the factors that lead family members to either hire or not hire a private companion, which has not been obtained before. It is hoped that indirect benefits will be achieved by using this information to develop appropriate policies, improve care, and advocate for funding.

Informed Consent:

By agreeing to participate in the study “To Hire or Not to Hire a Private Companion: Factors Contributing to the Decision”, I understand:

- I have been asked to complete a questionnaire;

- my participation is entirely voluntary and by completing this questionnaire and returning it to the researcher I am voluntarily consenting to participate in the study;

- I can withdraw from the study at any time;

- my participation in the study will not affect access to services for me, my older relative, or the private companion;

- if I choose to withdraw from the study, I can decide to withdraw the information up until that point;

- there is no financial compensation for my time;

- the procedures of the study, the risks and benefits of participation, and my right to confidentiality;

- all information collected as part of this research will be kept confidential and that I will not be identified in any way, in any publication of the results;

- if I have questions about the study now or in the future that are not answered in this information sheet, I can contact the researcher to have my questions answered.

If you want to discuss this study further, or you have any concerns with this study, please contact Julie Dergal at (416) 785-2500 ext. 2159, or by email julie.dergal@utoronto.ca. You may also contact Dr. Lynn McDonald, Professor, Faculty of Social Work and Doctoral Supervisor at (416) 978-6314 or at lynn.mcdonald@utoronto.ca. If you wish to contact someone not connected with this project about your rights as a research participant, please feel free to call Dr. Ron Heslegrave, Chair of the Research Ethics Board at (416) 785-2500 ext. 2190. This person is not involved with the research project in any way and calling him will not affect your participation in the study.
Study Questionnaire #1

You are being asked to complete **two forms:** the yellow form, and either the blue form or the green form.

(Note: Throughout the study questionnaires, the words “family member”, and “relative” are used. However, we recognize that friends and guardians will also receive these questionnaires and we would like you to complete them as well.)

EVERYONE PLEASE COMPLETE STUDY QUESTIONNAIRE #1 – YELLOW

and

Family members whose relative has EVER had a private companion (e.g. now or in the past), please complete Study Questionnaire #2 – GREEN.

Family members whose relative has NEVER had a private companion, please complete Study Questionnaire #3 – BLUE.

Thank you for your time. The information you provide is extremely valuable!
STUDY QUESTIONNAIRE #1
Note: Throughout the questionnaire the words “family member” and “relative” are used. However, please answer the questions based on the person you are caring for, regardless of your relationship to him/her.

A. Information about Your Relative

1. The older adult in the nursing home is your:
   □ mother       □ uncle
   □ father       □ aunt
   □ husband      □ mother-in-law
   □ wife         □ father-in-law
   □ brother      □ friend
   □ sister       □ other (specify) ______

2. a. How long has your relative been in the nursing home?
   ______________________________________
   (# of months since admission)

3. What is the age of your relative?
   ______________________________
   (age in years)

4. a. Do you think your relative has some form of dementia?
   □ yes
   □ no

   b. If yes, it is:
      □ mild
      □ moderate
      □ severe

5. How physically demanding do you think it is for the staff to provide care to your relative?
   □ not at all
   □ a little
   □ moderately
   □ very
   □ extremely

B. Information about You

1. How long did you look after your relative (e.g. help with laundry, food, shopping, care):

   a. BEFORE he/she was admitted to the nursing home:
      __________________________ / ________________
      (# of yrs)  (# of months)

   b. AFTER he/she was admitted to the nursing home:
      __________________________ / ________________
      (# of yrs)  (# of months)

2. Overall, how would you rate your health:
   □ poor □ fair □ good  □ very good □ excellent

3. On average, how many days per week do you visit your relative in the nursing home?
   ____________________________
   (# of days)

4. a. Do you live in Ontario?  □ yes
   □ no

   b. If yes, how long does it take you to get to the nursing home?
      ____________________________ / ________________
      (# of hours)  (# of minutes)

5. a. Is it difficult for you to get to the nursing home?
   □ yes
   □ no

   b. If yes, check which reasons explain why:
      □ transportation
      □ time constraints
      □ cost
      □ geographic distance
      □ other ____________________________
C. Information about Your Experience of Caring for Your Relative

Even though your relative is living in the nursing home, we recognize that you still provide some physical, social, and/or emotional care to him/her.

Please answer the following three sections based on your experience with caring/caregiving.

1. How involved are you in the following:

   Extent of Involvement (check one per statement)
   
   not at all  a little  moderately  very  extremely
   
   a. the overall daily care of your relative  □  □  □  □  □
      (e.g. laundry, shopping, discussions with staff)
   b. the physical needs of your relative  □  □  □  □  □
      (e.g. grooming, feeding)
   c. the emotional needs of your relative  □  □  □  □  □
      (e.g. conversation/emotional support)
   d. the social needs of your relative  □  □  □  □  □
      (e.g. outings, taking relative to activities)
   e. the financial needs of your relative  □  □  □  □  □
      (e.g. cost of clothes, personal belongings, extra care)

2. Please rate whether you agree or disagree with the following statements.

   Extent you agree or disagree (check one per statement)
   
   strongly disagree  disagree  neutral  agree  strongly agree
   
   a. I enjoy providing care to my relative.  □  □  □  □  □
   b. I get satisfaction out of caregiving.  □  □  □  □  □
   c. Caregiving has given my self-esteem a boost.  □  □  □  □  □
   d. My relative shows appreciation for what I do.  □  □  □  □  □
   e. Providing care to my relative gives my life meaning.  □  □  □  □  □
Since your relative has been in the nursing home, how often do you feel the following statements are true.

**Frequency Statements are True (check one per statement)**

<table>
<thead>
<tr>
<th></th>
<th>never</th>
<th>rarely</th>
<th>sometimes</th>
<th>often</th>
<th>all of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. You have less energy.</td>
<td></td>
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<tr>
<td>b. You feel physically strained.</td>
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<td>c. Your health has suffered.</td>
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<tr>
<td>d. Your social life has suffered.</td>
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<td>e. You’ve had to give up trips/vacations.</td>
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<td>f. You are able to go out.</td>
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<td>g. You had to adjust your schedule (work/home).</td>
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<td>h. Caregiving is a financial strain.</td>
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<tr>
<td>i. You resent the extra cost of caregiving.</td>
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<td>j. You have had no time to do things you need to do.</td>
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<td>k. You have no time to yourself.</td>
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<tr>
<td>l. You feel resentful toward your relative.</td>
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<td>m. You feel angry toward your relative.</td>
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<td>n. You feel your relationship with your relative is strained.</td>
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<td>o. You are glad that you can provide care to your relative.</td>
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<tr>
<td>p. You feel your relative tries to manipulate you.</td>
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<td>q. You feel your relative is overly demanding.</td>
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<tr>
<td>r. You resent the loss of time spent caregiving.</td>
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<td>s. You are able to spend time in recreational activities.</td>
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<td>t. You are under more stress due to caregiving.</td>
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</tbody>
</table>
Frequency Statements are True (check one per statement)

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</thead>
<tbody>
<tr>
<td>u. You feel that your relative is more dependent.</td>
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<td>v. Your sleep is disturbed because of caregiving.</td>
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<tr>
<td>w. You don’t have enough money to support yourself and your relative.</td>
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<tr>
<td>x. You are pleased about your relationship with your relative.</td>
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</table>

D. Information about Your Social Supports

1. a. Overall, how much tangible support do you receive (e.g. someone provides you with assistance like transportation, cares for a family member while you are away, gives/loans you money)?
   - [ ] none
   - [ ] a little bit
   - [ ] some
   - [ ] quite a bit
   - [ ] a great deal

b. Overall, how satisfied are you with the amount of tangible support you receive?
   - [ ] not at all
   - [ ] a little bit
   - [ ] somewhat
   - [ ] very
   - [ ] extremely

2. a. Overall, how much emotional support do you receive (e.g. someone is available in a stressful situation, comforts you, listens to you talk, expresses empathy and concern)?
   - [ ] none
   - [ ] a little bit
   - [ ] some
   - [ ] quite a bit
   - [ ] a great deal

b. Overall, how satisfied are you with the amount of emotional support you receive?
   - [ ] not at all
   - [ ] a little bit
   - [ ] somewhat
   - [ ] very
   - [ ] extremely

3. a. Overall, how much informational support do you receive (e.g. someone suggests how to solve a problem, gives you advice, information, guidance or feedback, directs you to assistance)?
   - [ ] none
   - [ ] a little bit
   - [ ] some
   - [ ] quite a bit
   - [ ] a great deal

b. Overall, how satisfied are you with the amount of informational support you receive?
   - [ ] not at all
   - [ ] a little bit
   - [ ] somewhat
   - [ ] very
   - [ ] extremely

4. List, in the order of importance, the relationship of the people who you feel give you the most overall support (e.g. no one, spouse, child, rabbi, friend, private companion). If you only have one or two people, you can leave spaces blank. If you do not have anyone, please fill in “no one”.

1. ______________________  2. ______________________  3. ______________________
E. Perceptions of Quality of Care

Following are examples of hassles you may experience in caring for a relative living in a nursing home. Some of these examples will have been a hassle for you recently, whereas others have not. Please check whether each of these statements has EVER been a hassle, and if YES, circle how much of a hassle it was.

<table>
<thead>
<tr>
<th>Hassle</th>
<th>Did it Happen? Check Yes or No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Staff member(s) being rude to you.</td>
<td>□ YES □ NO</td>
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<tr>
<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<tr>
<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>2. Resident’s complaints about staff members.</td>
<td>□ YES □ NO</td>
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<tr>
<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>3. Receiving phone calls at home from the nursing home facility.</td>
<td>□ YES □ NO</td>
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<tr>
<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>4. Needing to tell the staff how to care for the resident.</td>
<td>□ YES □ NO</td>
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<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>5. Ways staff handles resident’s behavioural problems.</td>
<td>□ YES □ NO</td>
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<td>If YES, circle how much of a hassle it was.</td>
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<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>6. Giving up other activities to visit resident.</td>
<td>□ YES □ NO</td>
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<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>7. Having to remind staff to do things for the resident.</td>
<td>□ YES □ NO</td>
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<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>8. Staff not taking personal interest in the resident.</td>
<td>□ YES □ NO</td>
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<td>If YES, circle how much of a hassle it was.</td>
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<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>9. Scheduling appointments for the patients.</td>
<td>□ YES □ NO</td>
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<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>10. Staff delays in completing paperwork.</td>
<td>□ YES □ NO</td>
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<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>11. Staff not treating the resident with dignity.</td>
<td>□ YES □ NO</td>
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<td>If YES, circle how much of a hassle it was.</td>
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<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>Hassle</td>
<td>Did it Happen? Check Yes or No</td>
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<tr>
<td>----------------------------------------------------------------------</td>
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<tr>
<td>12. Feeling left out of decisions made about resident.</td>
<td>□ YES □ NO</td>
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<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>13. Staff leaving resident ungroomed/untidy.</td>
<td>□ YES □ NO</td>
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<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>14. Having to remain in constant contact with nursing care facility.</td>
<td>□ YES □ NO</td>
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<td>If YES, circle how much of a hassle it was.</td>
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<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>15. Staff complaining to you about the resident.</td>
<td>□ YES □ NO</td>
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<td>If YES, circle how much of a hassle it was.</td>
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<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>16. Staff speaking about resident as if the resident were not there.</td>
<td>□ YES □ NO</td>
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<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>17. Not being able to leave the local area for short trips.</td>
<td>□ YES □ NO</td>
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<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>18. Staff making you feel unwelcome.</td>
<td>□ YES □ NO</td>
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<td>If YES, circle how much of a hassle it was.</td>
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<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>19. Staff ignoring resident’s requests.</td>
<td>□ YES □ NO</td>
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<td>If YES, circle how much of a hassle it was.</td>
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<tr>
<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>20. Staff’s phone calls asking you to bring things for the resident.</td>
<td>□ YES □ NO</td>
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<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>21. Difficulty interacting with resident’s physician.</td>
<td>□ YES □ NO</td>
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<td>If YES, circle how much of a hassle it was.</td>
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<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>22. Staff expecting you to be available at any time.</td>
<td>□ YES □ NO</td>
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<tr>
<td></td>
<td>If YES, circle how much of a hassle it was.</td>
</tr>
<tr>
<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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</tbody>
</table>
## Hassle

<table>
<thead>
<tr>
<th>Hassle</th>
<th>Did it Happen? Check Yes or No</th>
</tr>
</thead>
<tbody>
<tr>
<td>23. Staff not encouraging patient to do things for self.</td>
<td>□ YES  □ NO</td>
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<tr>
<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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<tr>
<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>24. Staff overmedicating resident.</td>
<td>□ YES  □ NO</td>
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<td>If YES, circle how much of a hassle it was.</td>
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<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>25. Staff leaving resident in pajamas all day.</td>
<td>□ YES  □ NO</td>
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<td>If YES, circle how much of a hassle it was.</td>
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<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
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<tr>
<td>26. Extra expenses due to providing care for the resident.</td>
<td>□ YES  □ NO</td>
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<td></td>
<td>If YES, circle how much of a hassle it was.</td>
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</tr>
<tr>
<td>27. Staff being intolerant toward the resident.</td>
<td>□ YES  □ NO</td>
</tr>
<tr>
<td></td>
<td>If YES, circle how much of a hassle it was.</td>
</tr>
<tr>
<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
</tr>
<tr>
<td>28. Staff not working with resident on exercise/therapy.</td>
<td>□ YES  □ NO</td>
</tr>
<tr>
<td></td>
<td>If YES, circle how much of a hassle it was.</td>
</tr>
<tr>
<td></td>
<td>it wasn’t a little bit somewhat quite a bit a great deal</td>
</tr>
</tbody>
</table>

② How much improvement do you think is NEEDED in the following care areas in the nursing home:

<table>
<thead>
<tr>
<th>Care Area</th>
<th>Extent of Improvement Needed (check one answer per care area)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Environment is “home like”</td>
<td>□ no improvement</td>
</tr>
<tr>
<td>b. Cleanliness of the facility</td>
<td>□ some improvement</td>
</tr>
<tr>
<td>c. Food selection</td>
<td>□ a great deal of improvement</td>
</tr>
<tr>
<td>d. Food service</td>
<td></td>
</tr>
<tr>
<td>e. Variety of activities</td>
<td></td>
</tr>
<tr>
<td>f. Noise level</td>
<td></td>
</tr>
<tr>
<td>g. Privacy during family visits</td>
<td></td>
</tr>
<tr>
<td>h. Management of medications</td>
<td></td>
</tr>
<tr>
<td>i. Amount of care provided by staff</td>
<td></td>
</tr>
<tr>
<td>j. Personalized attention by staff</td>
<td></td>
</tr>
<tr>
<td>k. Managing concerns/complaints</td>
<td></td>
</tr>
<tr>
<td>l. Social stimulation</td>
<td></td>
</tr>
<tr>
<td>m. Respect for resident’s autonomy</td>
<td></td>
</tr>
<tr>
<td>n. Meaningful relationships</td>
<td></td>
</tr>
<tr>
<td>o. Preserve dignity of resident</td>
<td></td>
</tr>
</tbody>
</table>

□ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □
F. Descriptive Characteristics about Yourself

Please answer the following questions so we may describe the group of people who respond to this questionnaire.

① What year were you born? __________
(year born)

② You are (check one):
□ male
□ female

③ What is your current marital status (check one)?
□ single (never married)
□ married
□ widowed
□ common law marriage
□ divorced
□ separated

④ What is your current/previous occupation?


⑤ In terms of PAID WORK, you are currently:
□ employed full-time
□ employed part-time
□ retired
□ retired from primary career but working
□ unemployed
□ other _______________________

⑥ What is the highest level of formal schooling you have completed?
□ _______________________
(# of years)

⑦ What is your total household income?
□ less than $25, 000
□ $25, 000 to $49, 999
□ $50, 000 to $74, 999
□ $75, 000 to $99, 999
□ $100, 000 to $124, 999
□ $125, 000 to $149, 999
□ $150, 000 or more

Thank you. In addition to this questionnaire, please complete:

Questionnaire #2 - GREEN if your relative has EVER (e.g. now or in the past) had a private companion at a nursing home

OR

Questionnaire #3 - BLUE if your relative has NEVER had a private companion at a nursing home

ONCE YOU HAVE COMPLETED THE GREEN OR BLUE QUESTIONNAIRE YOU ARE FINISHED. PLEASE RETURN THE QUESTIONNAIRES IN THE PRE-ADDRESSED STAMPED ENVELOPE PROVIDED.
QUESTIONNAIRE #2 – EVER had a Private Companion at the Nursing Home (e.g. now or in the past)

Note: Throughout the questionnaire the words “family member” and “relative” are used. However, please answer the questions based on the person you are caring for, regardless of your relationship to him/her.

A. Information about Your Relative

1. The week before your relative came to the nursing home, he/she:
   - □ lived alone
   - □ lived with you
   - □ lived with another family member
   - □ lived in another nursing home
   - □ transferred from a hospital
   - □ other (specify) __________

2. Was a private companion helping him/her there?
   - □ yes
   - □ no

2. Overall, how long has your relative had a private companion?
   __________ / __________ (# of years) (# of months)

3. How many private companions currently work with your relative?
   __________

4. For each private companion currently working with your relative, answer the following questions. If your relative does not currently have a private companion, please fill in the table below based on the most recent occasion that a private companion(s) worked with him/her.

<table>
<thead>
<tr>
<th>Private Companion</th>
<th>Male or Female (M or F)</th>
<th>First Language Spoken (English or other)</th>
<th>Highest Level of Education (specify or don’t know)</th>
<th>Previous Experience working with Older People (Yes, No, or Don’t know)</th>
<th>Specialized Training with Older People (Yes, No, or Don’t know)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
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<tr>
<td>3</td>
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<tr>
<td>4</td>
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<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
B. The Reasons for Hiring a Private Companion(s)

1. Were you involved in hiring the private companion? □ YES □ NO

2. Please CHECK ALL of the following reasons that explain why a private companion was hired.

1) Needs of Family
   Yes  No
   □  □ family concerned about quality of care (e.g. expectations not being met, not enough staff)
   □  □ family experienced burden related to helping relative
   □  □ family’s emotional state (e.g. guilt, worry, stress)
   □  □ family was unable to visit/be involved with the relative as much as they would like due to:
      □ work □ child demands □ geographic distance □ own health status
      □ other ____________________________
   □  □ few other family members/friends available to share the responsibility

2) Needs of Relative
   Yes  No
   □  □ relative’s health condition worsened and he/she needed more care (e.g. with feeding)
   □  □ relative needed more personalized attention (e.g. with grooming, dressing)
   □  □ relative needed more emotional support (e.g. lonely)
   □  □ relative needed more social interaction
   □  □ relative needed help getting around (e.g. walks, programs, outside)

3) Impressions of Private Companions
   Yes  No
   □  □ private companions are available at a reasonable cost
   □  □ private companions were recommended - if YES, please check by whom:
      □ your relative
      □ you/other family members
      □ other residents’ family members
      □ staff
   □  □ many other residents have a private companion

4) Any other reason(s) a private companion was hired?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
C. Description of Private Companions Services

1. In total, how many days per week does a private companion(s) work with your relative? ________________________ (# of days/wk)

2. In total, about how many hours/week does a private companion(s) work with your relative? ________________________ (# of hrs/wk)

3. a. When does a private companion usually work with your relative?
   - only weekdays
   - only weekends
   - both weekdays and weekends
   - only holidays
   - other ________________________________

b. What parts of the day does the private companion work with your relative? (check all that apply)
   - yes no getting ready in the morning
   - yes no breakfast time
   - yes no morning activities
   - yes no lunch time
   - yes no afternoon activities
   - yes no dinner time
   - yes no evening activities
   - yes no bedtime
   - yes no after bedtime
   - yes no other ________________________________

4. How often, in the last month, did you talk to the private companion about your relative?
   - never
   - once a month
   - few times a month
   - once a week
   - few times a week
   - daily
   - other ________________________________

5. Approximately how much do private companion services cost per week for your relative? ________________________ ($$ / week)

D. The Role of Private Companions

1. Overall, how much tangible support do you receive from the private companion (e.g. provides transportation, cares for a family member while you’re away, purchases items needed, assists with scheduling)?
   - none
   - a little bit
   - some
   - quite a bit
   - a great deal

2. Overall, how much emotional support do you receive from the private companion (e.g. is available in a stressful situation, comforts you, listens to you talk, expresses empathy and concern)?
   - none
   - a little bit
   - some
   - quite a bit
   - a great deal

3. Overall, how much informational support do you receive from the private companion (e.g. suggests how to solve a problem, gives you advice, information, guidance or feedback, directs you to assistance)?
   - none
   - a little bit
   - some
   - quite a bit
   - a great deal
The following duties are commonly performed by private companions. Please check all of the following duties the private companion(s) provides to your relative.

<table>
<thead>
<tr>
<th>Duties Provided to Your Relative by the Private Companion(s)</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Activities of Daily Living:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathing/showering/washing-up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basic mouth care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dressing and undressing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nail care – hands/foot</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hair combing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Application of cream/lotion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shaving</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make-up application</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2. Ambulation and Mobility:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfer from bed to chair/ chair to chair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help with adaptive aids/prosthesis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help with exercise or walking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accompany resident to and from appointments</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>3. Toileting:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help resident to toilet upon request</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change or help with the changing of incontinence briefs/pads</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Report bowel movements or changes in elimination patterns</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>4. Nutrition:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help with feeding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help with drinking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provide snacks/drinks</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>5. Medical Assistance:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Check tubes (e.g. Foley catheter, feeding tube) are free of kinks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provide assistance when medications are administered</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Report any changes in the physical or emotional comfort of the resident</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>6. Emotional/Social Support:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Escort resident to social/recreational activities of choice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participate with the resident in social/recreational events</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provide companionship and conversation to the resident</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shop for items as needed/requested by resident or family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help with using the telephone</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>7. Physical Environment:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Position bed or chair to promote comfort</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organize/do laundry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tidy room, drawers, cupboards</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make the bed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Report any cleaning, maintenance or safety issues to staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>8. Other:</strong> <em>(please list all other duties provided)</em></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
E. Information About Your Private Companion Services

① Who pays for the private companion services?
☐ only your relative in the nursing home
☐ your relative and one family member
☐ your relative and several family members
☐ one family member only
☐ several family members
☐ friend
☐ other ____________________________

② Is it a financial burden for whoever pays for the private companion(s)?
☐ yes
☐ no

③ Do you think private companion services should be subsidized by the government?
☐ yes
☐ no

④ Overall, how satisfied are you with the services the private companion(s) provides to your relative?

☐ ☐ ☐ ☐ ☐ ☐
not at all a little somewhat very extremely

⑤ Additional Comments:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

PLEASE ENCLOSE THE QUESTIONNAIRES IN THE PRE-ADDRESSED STAMPED ENVELOPE AND MAIL.

Thank you for your time.

Your participation is very much appreciated!
QUESTIONNAIRE #3 – NEVER had a Private Companion at the Nursing Home

Note: Throughout the questionnaire the words “family member” and “relative” are used. However, please answer the questions based on the person you are caring for, regardless of your relationship to him/her.

A. Information about Your Relative

① a. In the week before your relative came to the nursing home, he/she:
   □ lived alone
   □ lived with you
   □ lived with another family member
   □ lived in another nursing home
   □ transferred from a hospital
   □ other (specify) __________

b. Was a private companion helping him/her there? □ yes
   □ no

B. Private Companion Status

① Check which of the following statements best describes your relative’s current situation:

□ My relative has never had a private companion at the nursing home and there IS NO plan to hire one at this time.
   If YES, GO TO C1a.

□ My relative has never had a private companion at the nursing home, but there IS a plan to hire one at this time.
   If YES, GO TO C1b.

C. Possible Factors Related to Hiring or Not Hiring Private Companions

C1a.

① a. Please check all of the reasons listed below that explain why your relative has never had a private companion.

1) Not Necessary

   Yes  No
   □  □ existing institutional care is adequate
   □  □ sufficient involvement of family and friends
   □  □ relative does not need one
2) Not Feasible

Yes  No
☐  ☐    not enough financial resources to hire a private companion
☐  ☐    not able to find a suitable private companion
☐  ☐    relative does not want one

3) Impressions of Private Companion

Yes  No
☐  ☐    do not understand what private companions do
☐  ☐    concerned with the risks associated with having a private companion
  (e.g. liability issues and safety of relative)
☐  ☐    have a negative impression of private companions

4) Any other reason(s) a private companion will not be hired?

__________________________________________________________________________

IF YOU ANSWERED C1a. SKIP C1b. and continue with question 2. page 3

C1b.

① Please CHECK ALL of the following reasons that explain why a private companion will be hired.

1) Needs of Family

Yes  No
☐  ☐    family concerned about quality of care (e.g. expectations not being met, not enough staff)
☐  ☐    family experienced burden related to helping relative
☐  ☐    family’s emotional state (e.g. guilt, worry, stress)
☐  ☐    family was unable to visit/be involved with the relative as much as they would like due to:
  ☐ work    ☐ child demands    ☐ geographic distance    ☐ own health status
  ☐ other    _______________________
☐  ☐    few other family members/friends available to share the responsibility
2) Needs of Relative

Yes  No

☐  ☐  relative’s health condition worsened and he/she needed more care (e.g. with feeding)
☐  ☐  relative needed more personalized attention (e.g. with grooming, dressing)
☐  ☐  relative needed more emotional support (e.g. lonely)
☐  ☐  relative needed more social interaction
☐  ☐  relative needed help getting around (e.g. walks, programs, outside)

3) Impressions of Private Companions

Yes  No

☐  ☐  private companions are available at a reasonable cost
☐  ☐  private companions were recommended – if YES, please check by whom:
  ☐  your relative
  ☐  you/other family members
  ☐  other residents’ family members
  ☐  staff

☐  ☐  many other residents have a private companion

4) Any other reason(s) a private companion will be hired?


② Do you think private companion services should be subsidized by the government?  ☐ yes
  ☐ no

③ Additional Comments:


PLEASE ENCLOSE THE QUESTIONNAIRES IN THE PRE-ADDRESSSED STAMPED ENVELOPE AND MAIL.

Thank you for your time.

Your participation is very much appreciated!
<table>
<thead>
<tr>
<th>Variable</th>
<th>Operationalization of Variable</th>
<th>Name of Scale</th>
<th>Source</th>
<th>Validated?</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Member Involvement In</td>
<td>Involvement reported on a 5-point scale from not at all to extremely, on five dimensions:</td>
<td>Family Member Involvement Scale</td>
<td>{Ejaz, 2002 #71}</td>
<td>No psychometrics</td>
<td>Previously used in caregiving studies</td>
</tr>
<tr>
<td>Resident Care</td>
<td>overall daily care, physical needs, emotional needs, social needs, financial needs</td>
<td></td>
<td>available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived Health</td>
<td>Family member reports health on a single item: 5-point scale (poor to excellent)</td>
<td>Single Item Self-reported Health Status</td>
<td>{Beach, 2000 #317}</td>
<td>No psychometrics</td>
<td>Extensively used throughout the literature, &amp; amongst caregivers</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>available</td>
<td></td>
<td>Highly correlated with objective measures of health</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Used in National Canadian Surveys (e.g. Canadian Community Health Survey)</td>
</tr>
<tr>
<td>Positive Aspects of Caregiving</td>
<td>Amount of satisfaction from caregiving derived from the sum of five questions, each ranging from</td>
<td>Caregiver Satisfaction Measure</td>
<td>{Lawton, 1989 #1377}</td>
<td>Reliability .67-.92</td>
<td>Chosen for its brevity commonly used and considered methodologically</td>
</tr>
<tr>
<td></td>
<td>1(strongly disagree) to 5 (strongly agree).</td>
<td></td>
<td></td>
<td>No validity data</td>
<td>rigorous</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Variable</td>
<td>Operationalization of Variable</td>
<td>Name of Scale</td>
<td>Source</td>
<td>Validated?</td>
<td>Comments</td>
</tr>
<tr>
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<td>------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------</td>
<td>----------------------------</td>
<td>-----------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>A higher score on the 18 items of the MCSI, each rated on a 5-point scale 1 (never) to 5 (all the time) indicated a higher level of burden (maximum score was 90)</td>
<td>Multi-Dimensional Strain Index (MCSI)</td>
<td>{Stull, 1996 #986}</td>
<td>Yes – construct validity &amp; good internal consistency (.55-85)</td>
<td>Not commonly used in the literature</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Chosen for its measurement of the multi-dimensions of burden and good psychometric properties</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Had been used among family members of nursing home residents</td>
</tr>
<tr>
<td>Social Support</td>
<td>Network Size (how many)</td>
<td>Norbeck Social Support Questionnaire &amp; Socially Supportive Behaviours (ISSB)</td>
<td>{Norbeck, 1981 #1408}</td>
<td></td>
<td>Modified Scales - combined elements of each to tap key dimensions</td>
</tr>
<tr>
<td></td>
<td>Network Composition (relationship of key sources of support in ranked order)</td>
<td></td>
<td>{Barrera, 1983 #978}</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Amount of Support Received (from 1 (none) to 5 (a great deal), indicated for each; overall, tangible, emotional, &amp; informational support)</td>
<td></td>
<td>{Krause, 1990 #976}</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Satisfaction with Support Received (from 1 (none) to 5 (a great deal), indicated for each; overall, tangible, emotional, &amp; informational support)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Figure 2 Continued: An Overview of Key Variables included in the Questionnaire

<table>
<thead>
<tr>
<th>Variable</th>
<th>Operationalization of Variable</th>
<th>Name of Scale</th>
<th>Source</th>
<th>Validated?</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Care</td>
<td>Number of negative events related to institutional stressors family members reported happened (range from 0-28)</td>
<td>The Nursing Home Hassles Scale</td>
<td>{Parris Stephens, 1991 #196}</td>
<td>Yes</td>
<td>One of the few standardized measures that captures quality of care</td>
</tr>
<tr>
<td></td>
<td>Number of negative events related to institutional stressors family members reported were hassles (range from 0-28)</td>
<td></td>
<td>test-retest reliability (.61-.82)</td>
<td></td>
<td>Has been previously used among family members of nursing home residents</td>
</tr>
<tr>
<td>Perceptions of Care</td>
<td>Number of areas of care that needed improvement (range 0-13) - none, some or a great deal</td>
<td>Perceptions of Care</td>
<td>{Cutler Riddick, 1992 #402; Ejaz, 2002 #71}</td>
<td>No psychometrics available</td>
<td>Modified – combined care areas from two sources</td>
</tr>
<tr>
<td>Private Companion (PC) Information</td>
<td>PC Duties: Activities performed (yes/no) Reasons PC Hired: Checklist of Reasons (yes/no)</td>
<td>Newly Developed Measures</td>
<td>{Goldhar, 2003 #463}</td>
<td>No</td>
<td>Previously used amongst family members of nursing home residents</td>
</tr>
</tbody>
</table>

Note: Questions related to the socio-demographic information of family members and the residents, as well as information related to the caregiving situation were drawn from existing national surveys (e.g. Canadian Community Health Survey) and are not listed in this table. For more detail on these variables see Section 4.4.2 in the text.
APPENDIX 3  Informed Consent and Interview Guide
Information Letter & Consent Form for Participating in an Interview

“To Hire or Not to Hire a Private Companion: Factors Contributing to the Decision”

Researcher: Julie Dergal MSc, Ph.D. Candidate, Faculty of Social Work, University of Toronto Graduate Student, Kunin-Lunenfeld Applied Research Unit (KLARU), Baycrest Phone: (416) 785-2500 ext. 2159 Email: julie.dergal@utoronto.ca

Funding: SSHRC Doctoral Award, Ontario Graduate Scholarship / Lupina Doctoral Fellowship

Study Information:
- I would like to invite you to participate in this study of families with and without private companions.
- In order to decide whether you wish to participate in this research study, it is important that you read and understand what the study entails.

Study Purpose and Importance:
- The purpose of this study is twofold: 1) to understand the factors associated with the families’ decision to either hire a private companion or not for their relative; 2) to understand the role private companions serve for families who hire them.

Study Involvement:
- Your involvement includes participation in a face-to-face interview that lasts about two hours and will be audio-recorded. If you are willing, you may be asked at a later date to review the results of the study to ensure that your ideas have been accurately captured and correctly represented.
- During the interview you will be asked about your experiences as a family member of an older adult in a nursing home, the factors that have contributed to your decision to hire a private companion or not, and the role private companions serve.
- The interview will take place in a location convenient for you.
- Your participation in this study is completely voluntary and you can decline to answer questions or withdraw from this study at any time. Should you choose to withdraw from the study during or after the interview, you may retract any information that has been collected up to that point.
- Your decision to participate, decline to participate, or withdraw from the study at any time will not affect access to any services you, your older relative, or the private companion receive.
- All data collection for this study will be conducted between August 2007 and December 2007.
- There is no financial compensation for participating in this study.

Confidentiality:
- Your relative, the private companion, or the staff, will not have access to the responses you have shared, and they will not know whether or not you participated in this study. All identifying information you provide such as your name will be replaced with a numerical code to protect your confidentiality.
- All data will be stored at the University of Toronto. All transcripts and tapes will be kept in a locked filing cabinet that is only accessible to the researcher and will be destroyed after the study is completed.
- All data will be reported in group form and used for scholarly purposes. I would be pleased to provide you with a summary of the results of this study upon your request.
Risks and Benefits:
- There are no risks attached to participating in this interview. However, the interview may raise issues that you find difficult to discuss.
- You may choose not to answer all or some of the questions, and you may withdraw from the study at any time.
- If you want to discuss the issues raised in the interview further, you may contact the researcher who will provide you with assistance.
- There are no direct benefits to you, your family or the private companion, for participating in this study. However, some family members may find discussing their experiences about having a relative in a nursing home helpful.
- Your participation in this study will provide valuable information about the factors that lead family members to either hire or not hire a private companion, which has not been obtained before. It is hoped that indirect benefits will be achieved by using this information to develop appropriate policies, improve care, and advocate for funding.

Informed Consent:
By agreeing to participate in the study “To Hire or Not to Hire a Private Companion: Factors Contributing to the Decision”, I understand:

- I have been asked to participate in a face-to-face interview that takes about two hours.
- my participation is entirely voluntary and I can withdraw from the study at any time
- my participation in the study will not affect access to services for me, for my older relative, or the private companion
- if I choose to withdraw from the study, I can decide to withdraw the information up until that point
- there is no financial compensation for my time
- the procedures of the study, the risks and benefits of participation, and my right to confidentiality
- all information collected as part of this research will be kept confidential and that I will not be identified in any way, in any publication of the results
- if I have questions about the study now or in the future that are not answered in this information sheet, I can contact the researcher to have my questions answered

If you have any questions or concerns about this study please contact Julie Dergal at (416) 785-2500 ext. 2159, or by email julie.dergal@utoronto.ca. You may also contact Dr. Lynn McDonald, Professor, Faculty of Social Work and Doctoral Supervisor at (416) 978-6314 or email lynn.mcdonald@utoronto.ca. If you wish to contact someone not connected with the project about your rights as a research participant, please call feel free to call Dr. Ron Heslegrave, Chair of the Research Ethics Board at (416) 785-2500 ext. 2190. This person is not involved with the research project in any way and calling him will not affect your participation in the study.

Signed Consent:
I ___________________________________________ consent to participate in this research study.

Please check the box to indicate that you consent to having the interview audio-recorded. ☐

Name (printed): ___________________________ Phone Number/Email: ___________________________
Signature: ___________________________ Date: ___________________________
Interview Guide for Family Member’s with Private Companions

1. **What is it like to have a relative living in a nursing home?**
   
   Probe: How has your life changed since your relative has been admitted to the nursing home?
   
   Probe: How has caregiving for your relative in a nursing home influenced your life, socially, financially, physically, emotionally?

2. **What is your experience of the care provided to your relative at the nursing home?**
   
   Probe: environment, relationships, respect/dignity/autonomy of relative, staff, food
   
   Probe: What do you feel are the important aspects of care for your relative?
   
   Probe: If you could change some things about the care your relative receives in the nursing home, what would they be?

3. **What made you decide to hire a private companion?**
   
   Probe: What influenced your decision?
   
   Probe: quality of care, family availability, stress, institutional norm

4. **What did you hire them to do? What do you see as the role?**
   
   Probe: types of responsibilities?

5. **What are the best parts of having a private companion? What would change if you could?**
   
   Probe: How does having a private companion help your relative?
   
   Probe: quality of care, relationship
   
   Probe: How does having a private companion help you and your family?
   
   Probe: stress, freedom

6. **Is there anything else you would like to tell me about that I haven’t already asked you?**
   
   Probe: Do you have any recommendations/suggestions for other family members having to admit their relative to a nursing home? What should they know? What do you wish you knew before? Would you do anything differently?
Interview Guide for Family Members’ without Private Companions

1. What is it like to have a relative living in a nursing home?
   Probe: How has your life changed since your relative has been admitted to the nursing home?
   Probe: How has caregiving for your relative in a nursing home influenced your life, socially, financially, physically, emotionally?

2. What is your experience of the care provided to your relative at the nursing home?
   Probe: environment, relationships, respect/dignity/autonomy of relative, staff, food
   Probe: What do you feel are the important aspects of care for your relative?
   Probe: If you could change some things about the care your relative receives in the nursing home, what would they be?

3. What made you decide not to hire a private companion for your relative?
   Probe: quality of care, family availability, financial constraints, pressure to hire?

4. Do you think not having a private companion has affected you or your family in any way?
   Probe: differences in care received, relationship, stress, freedom
   Probe: What function do you think private companion serve?
   Probe: companionship, social activities, feeding, personal care

5. Is there anything else you would like to tell me about that I haven’t already asked you?
   Probe: Do you have any recommendations/suggestions for other family members having to admit their relative to a nursing home? What should they know? What do you wish you knew before? Would you do anything differently?
Notification of REB Continued Approval

Date: August 26, 2010

To: Dergal, J., McDonald, L.

Re: Family Caregivers and their Use of Private Companions in Nursing Homes (REB# 06-09)

REB Review Type: Annual
REB Initial Approval Date: August 10, 2007
REB Expiry Date: October 31, 2010
Consent Form(s) Currently Approved for Use: ICF (Version #3, February 14, 2007)

The above-named study has received continued approval from the Baycrest Research Ethics Board (REB) until the expiry date noted above. If the study is expected to continue beyond the expiry date, you are responsible for ensuring the study receives re-approval. The REB must also be notified of the completion or termination of this study and a final report provided.

If, during the course of the research, there are any serious adverse events, confidentiality concerns, changes in the approved project, or any new information that must be considered with respect to the project, these should be brought to the immediate attention of the REB. In the event of a privacy breach, you are responsible for reporting the breach to the Baycrest REB and the Baycrest Privacy Office (in accordance with Ontario health privacy legislation – Personal Health Information Protection Act, 2004). Additionally, the Baycrest REB requires reports of inappropriate/unauthorized use of the information. As the Principal Investigator, you are responsible for the ethical conduct of this study.

The Baycrest Research Ethics Board operates in compliance with the Tri-Council Policy Statement, ICH/GCP Guidelines, the Ontario Personal Health Information Protection Act (2004), and Part C, Division 5 of the Food and Drug Regulations of Health Canada.

Sincerely,

[Signature]

Angela Troyer, Ph.D.
Chair, Baycrest Research Ethics Board
APPENDIX 5 Qualitative Sample Participant Table
Table 1: The Characteristics of Family Member Participants in the Qualitative Sample

<table>
<thead>
<tr>
<th>Participant /Family member</th>
<th>Relationship of Family Member to Older Adult in Nursing Home</th>
<th>Age of Family Member</th>
<th>Employment Status of Family Member</th>
<th>Older Adult in Nursing Home Had Dementia</th>
<th>Private Companion Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Daughter caring for mother</td>
<td>72</td>
<td>Retired</td>
<td>Yes</td>
<td>2, Full-time 2, Part-time</td>
</tr>
<tr>
<td>2</td>
<td>Daughter caring for mother</td>
<td>67</td>
<td>Retired</td>
<td>No</td>
<td>2, Full-time</td>
</tr>
<tr>
<td>3</td>
<td>Daughter caring for mother</td>
<td>62</td>
<td>Working Full-time</td>
<td>Yes</td>
<td>2, Part-time</td>
</tr>
<tr>
<td>4</td>
<td>Daughter caring for mother</td>
<td>78</td>
<td>Retired</td>
<td>No</td>
<td>None</td>
</tr>
<tr>
<td>5</td>
<td>Daughter caring for mother</td>
<td>55</td>
<td>Working Part-time</td>
<td>No</td>
<td>None</td>
</tr>
<tr>
<td>6</td>
<td>Daughter caring for father</td>
<td>62</td>
<td>Working Full-time</td>
<td>Yes</td>
<td>1, Part-time</td>
</tr>
<tr>
<td>7</td>
<td>Son caring for father</td>
<td>67</td>
<td>Working Full-time</td>
<td>No</td>
<td>None</td>
</tr>
<tr>
<td>8</td>
<td>Husband caring for wife</td>
<td>87</td>
<td>Retired</td>
<td>Yes</td>
<td>1, Part-time</td>
</tr>
<tr>
<td>9</td>
<td>Husband caring for wife</td>
<td>89</td>
<td>Retired</td>
<td>Yes</td>
<td>1, Full-time</td>
</tr>
<tr>
<td>10</td>
<td>Husband caring for wife</td>
<td>96</td>
<td>Retired</td>
<td>Yes</td>
<td>1, Part-time</td>
</tr>
</tbody>
</table>