

**LES VISITES, UNE FAÇON D'ÊTRE: EXPÉRIENCES DE FRANCO-  
MANITOBAINS QUI RENDENT VISITE À DES MEMBRES DE LEUR  
FAMILLE DANS DES ÉTABLISSEMENTS DE SOINS DE LONGUE DURÉE**

**VISITING AS A WAY OF BEING:  
EXPERIENCES OF FRANCO-MANITOBANS  
WHO VISIT FAMILY MEMBERS IN LONG-TERM CARE**

by

Micheline St-Hilaire

A Thesis submitted to the Faculty of Graduate Studies of the University of Manitoba

in partial fulfillment of the requirements for the degree of

Master of Science

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**Les Visites, Une Façon D'être: Expériences de Franco-Manitobains Qui Rendent  
Visite à Des Membres de Leur Famille Dans Des Établissements de Soins de Longue  
Durée**

**Visiting As a Way of Being: Experiences of Franco-Manitobans Who Visit Family Members  
in Long-Term Care**

**BY**

**Micheline St-Hilaire**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University  
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**of**

**Master of Science**

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À mes grands-parents...

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## ABSTRACT

An ethnographic method was used to investigate the visiting experiences of Franco-Manitobans in two urban long-term care settings. Minimal research has been conducted in Canada to examine the visiting experience of family members. In Manitoba, no literature exists to describe the particular experiences of Franco-Manitobans in long-term care. Ten family visitors and nine residents participated in a focused ethnography to better understand the visiting experience. The data collection involved initial fieldwork, face-to-face interviews with visitors and participant observations with the nine visitor-resident dyads. Symbolic interactionism guided the study which examined what visitors actually did when they visited, determined whether participants differentiated between visiting and caregiving, identified the opportunities and challenges experienced by visitors, and explored the specific experiences of Franco-Manitobans who visit kin in long-term care settings. This study addressed the gap in our knowledge about the experiences of visitors, contributed to our understanding of the major factors associated with visiting in long-term care facilities, and provided insight to the experiences of Franco-Manitoban visitors.

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## PRÉCIS<sup>1</sup>

### Introduction

Le fait de visiter un membre de la famille dans un établissement de soins de longue durée peut être considéré comme un préalable aux soins, ou simplement une forme d'interaction sociale (Minichiello, 1989; Ross, 1997). D'autre part, les visites ont été décrites par certains comme l'aspect le plus important des soins prodigués à un membre de la famille dans un établissement de soins de longue durée. Le maintien des liens familiaux est essentiel à la qualité de vie des résidants, car ces derniers contribuent à la satisfaction de vivre, à un bon moral, et au sentiment d'avoir en mains les guides de sa propre vie (Arling, Harkins, et Capitman, 1986; Greene et Monahan, 1982; Harel et Noelker, 1982). Le but de cette recherche était d'étudier les expériences vécues par les personnes qui rendent visite à un membre de leur famille dans un établissement de soins de longue durée. La documentation existante sur l'hébergement des personnes âgées en établissement, traite surtout des signes annonciateurs de la nécessité d'un placement, des questions relatives à la prise de décision, de la période de transition, et de la participation de la famille aux activités de l'établissement (Naleppa, 1996). Elle accorde moins d'importance aux attitudes subjectives et à la signification des expériences et des problèmes relatifs aux visites à un parent âgé dans un établissement de soins de longue durée (Gubrium et Sankar, 1994).

Au Canada, très peu de chercheurs se sont intéressés spécifiquement aux familles qui continuent d'être mêlées à la vie de leurs parents âgés après que ces derniers ont été

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<sup>1</sup> Le précis suivant traduit les principales composantes et les constatations importantes de ce projet de recherche. The following précis is a translation of the main components and findings of this research project.

placés dans un établissement de soins de longue durée. Et on ne s'est pas attardé non plus à cette question chez les Franco-Manitobains bien que, dans le domaine de la gérontologie en général, on se soit penché sur les rapports qui existent entre l'appartenance à un groupe ethnique et son incidence sur le système d'aide à la famille (Driedger et Chappell, 1987). La présente étude traite plus particulièrement des expériences vécues par les Franco-Manitobains qui rendent visite à un membre de leur famille dans un établissement de soins de longue durée.

### Méthodologie

Il a semblé plus approprié d'aborder le sujet sous l'angle qualitatif.

L'ethnographie ciblée se prêtait bien à l'étude des visites comme expérience culturelle dans un contexte francophone, et c'est cette méthode que j'ai utilisée.

Dix visiteurs et neuf résidants de deux centres francophones de soins de longue durée ont participé à l'étude. Les visiteurs étaient apparentés par le sang ou par alliance à une personne résidante (apte à consentir à sa participation à la recherche); ils avaient passé du temps avec cette personne; et s'identifiaient comme Franco-Manitobains.

La collecte des données a nécessité un travail initial sur place, des entrevues et des observations. Le travail initial sur place était essentiel à l'établissement du contexte des visites. On a arrangé des entrevues d'une à deux heures environ avec les visiteurs, puis on a procédé à l'observation des participants (visiteurs et résidants) durant les visites. Les données ont été analysées selon la stratégie analytique de Wolcott (1994) en vue de dégager des thématiques relatives à l'expérience des visites. Cette analyse comprenait une démarche descriptive, analytique et interprétative.

## Exploration du vécu des visiteurs

Afin de mieux comprendre le vécu des visiteurs, il m'a fallu étudier le contexte des visites, tenter de définir le concept, et examiner plus en profondeur la dynamique inhérente aux visites. En ce qui a trait au contexte, j'ai dû cerner le profil des participants et définir le cadre des visites. À première vue, rendre visite semble être une action simple et directe. L'acte de rendre visite est toutefois plus complexe qu'on ne le croirait au premier abord. Certaines hypothèses relatives aux situations habituelles dans lesquelles se déroule une visite nous aideront à mieux déterminer ce qu'est une visite.

Dans des circonstances habituelles, la visite est un acte social par lequel deux catégories essentielles, celle des visiteurs, et celle des personnes visitées, entrent en relation dyadique. Une visite prend corps en présence de certains comportements fondamentaux essentiels : le visiteur et la personne visitée se saluent, ils passent du temps ensemble, puis se quittent. Ces éléments communs ressortaient de façon évidente dans les expériences de visite vécues en établissement de soins de longue durée. Par contre, c'est beaucoup plus que cela, une visite, surtout en établissement de soins de longue durée! La définition du mot visite proposée par le dictionnaire nous met sur la piste : *Le Petit Robert* définit le mot visite comme « Le fait d'aller voir quelqu'un et de rester avec lui un certain temps; le fait de recevoir un visiteur; l'action de visiter un client; le fait de se rendre dans un lieu pour voir, pour parcourir, pour visiter. » (*Le Petit Robert*, p. 2400). Assez souvent, le mot « visite » véhicule les notions d'amitié, de camaraderie et de compassion. De toute évidence, il ressort que cela n'est pas toujours le cas pour tous les visiteurs. Dans sa forme la plus élémentaire, une visite, c'est passer du temps avec quelqu'un à un endroit donné. La documentation relative à la participation des familles

aux activités d'un établissement de soins de longue durée met surtout l'accent sur les tâches à accomplir, c'est-à-dire comment « prendre soin » de quelqu'un. Selon *Le Petit Robert*, « prendre soin » c'est : « penser à; s'occuper de; soigner; s'occuper du bien-être de quelqu'un; actes par lesquels on soigne. » (*Le Petit Robert*, p. 2104). Nous savons bien que la « tâche » de visiter comporte bien d'autres aspects. Cette étude se propose donc d'aller au-delà d'une définition de la visite qui se limiterait à la notion de tâche, et d'approfondir le concept de « prendre soin » de quelqu'un.

Encore une fois, la définition du dictionnaire nous met sur une piste. *Le Petit Robert* définit l'expression « se soucier de » comme suit : « prendre intérêt à, avoir la préoccupation de... s'inquiéter, se tourmenter... ». Il faut donc étudier plus en détail la dynamique des visites aux personnes âgées.

Une visite dans un foyer pour personnes âgées qui se veut satisfaisante devient une entreprise délicate et précaire, tant du côté de la personne qui visite que de celui de la personne visitée. Il faut bien comprendre tout ce qu'une visite suppose et, pour ce faire, en examiner tous les éléments qui ont un impact sur la qualité de la visite dans un établissement de soins de longue durée. Dans les sections suivantes, j'approfondis la dynamique de la visite (s'engager, faire des activités, entrer en relation, adopter un point de vue, accepter de jouer un rôle) en vue de cerner un concept apparemment simple et direct, mais qui se révèle complexe et ambigu. La section qui suit donne la parole aux participants et aux visiteurs, lesquels nous font connaître leurs expériences.

S'engager. Il est essentiel de comprendre comment ces personnes en arrivent à prendre l'engagement de visiter un résident d'un établissement de soins de longue durée. Certains participants n'y voyaient que le côté pratique. D'autres manifestaient une

certaine ambivalence et certains se résignaient. Un des participants, plutôt ambivalent, décrivait son engagement en ces termes :

Je pense que c'est une erreur, parce que je la visite, puis je vois que son moral est toujours bas. Et pas rien que ça, je veux dire, elle a tellement changé, je ne sais pas si c'est à cause du stroke ou si les médicaments l'on changé... puis le problème est, c'est que ce n'est plus la même femme, ce n'est plus la femme que je connaissais (I3, 76-85).

Il déclare aussi :

Comme c'est là, je pense qu'elle est probablement où est-ce qu'elle devrait être et nous autres, notre rôle comme enfants, c'est de s'assurer qu'elle n'est pas oubliée et de venir la voir assez souvent et lui dire qu'on l'aime (I3, 529-535).

Faire des activités. Il est également essentiel de comprendre ce que les personnes font durant la visite et pourquoi elles le font. Elles ont pour responsabilité de répondre aux besoins physiques, psychologiques, sociaux et spirituels des résidants. Pour ce faire, elles doivent effectuer le « travail » relié à la visite. Quelles sont ces tâches ? Simone les décrit comme suit :

Ça fait que ce n'est plus plaisant, nos visites. Comme on les garde courtes. Moi, je viens souvent et elle aussi, je viens régulièrement, comme à peu près cinq fois par semaine, mais des fois, après quinze ou vingt minutes, quand j'en peux plus, je dis bye-bye papa, je reviendrai demain ou après demain (I7B, 99-107).

Au cours des entrevues, les participants mettaient l'accent sur l'aspect social de la visite, qu'ils qualifiaient habituellement d'agréable. Toutefois, les participants relevaient aussi des aspects plus ennuyeux de la visite, comme le rapportent les propos de Simone. Les personnes qui visitaient un résidant en mesure de donner son consentement, mettaient d'abord l'accent sur les activités de socialisation et de relation, mais un bon nombre ont également fait référence à des activités de la vie quotidienne comme brosser les cheveux, laver les dents et faire la lessive.

Entrer en relation. Un autre aspect important est la façon dont les visiteurs entrent en relation avec les autres personnes présentes dans l'établissement, car l'expérience de la visite dans son ensemble découle des interactions continues avec les autres. Il était



donc important de savoir avec qui les participants entraient en relation dans le cadre de la visite.

Le contact entre le visiteur et les autres personnes présentes dans l'établissement semble contribuer à l'agrément de la visite. Ces prises de contact constituent une forme de soutien dans l'établissement de soins de longue durée. Simone, la fille de Lucien, ne venait qu'après l'heure du souper. Elle disait préférer venir à des moments où elle avait l'occasion de rencontrer d'autres personnes.

Tu vois, moi, quand je viens, je l'amène en avant, puis là des fois il y a d'autres qui viennent et on jase un peu, puis là, lui s'intègre à cette conversation... On lui donne tout le temps son café – nous autres, je viens toujours au café... Bien je ne sais pas si c'est important pour lui, mais c'est important pour moi. Bien, tu sais, après une journée de travail, moi, j'ai besoin de m'asseoir puis me détendre, puis j'aime ça dans l'entrée, et le monde entre et sort, puis ça nous donne quelque chose à jaser, puis on prend notre café. Bien tu viens que tu développes avec les autres membres des familles. Bien il y en a beaucoup – c'est francophone, on connaît beaucoup de gens ici, en général, puis tu leur parles – un petit mot ici et là, puis c'est le fun (I7B, 1098-1142).

Il arrivait aussi que la présence des autres soit perçue comme un inconvénient.

Dans certains cas, la personne visitée ne se réjouissait pas toujours de la présence d'autres résidents, car elle avait alors l'impression de leur sacrifier un peu de son temps de visite.

Bien que les interactions entre les visiteurs et le personnel ne relèvent pas nécessairement de cette étude, les visiteurs avaient tendance à en parler, car ces interactions avaient des conséquences sur l'expérience vécue. Dans le cadre de cette étude, la plupart des relations entre le personnel et les visiteurs pouvaient être qualifiées d'associatives. Voici comment Jocelyne décrit son expérience :

On ne nous parle jamais des soins - ouais... c'est bizarre... après on reçoit un appel à ce sujet-là (l'odeur corporelle de sa mère). Non, à part le fait qu'il faut signer un registre lorsque nous la sortons, des choses comme ça - ou parfois,

lorsque j'arrive, ils sont en train de lui donner une piqûre ou quelque chose comme ça (I5, 1073-1080).

Les entrevues et les observations ont révélé sans l'ombre d'un doute que les interactions avec le personnel étaient limitées, ce qui mettait la plupart des visiteurs à l'aise. Le fait qu'on n'ait pas clairement défini quelles étaient les tâches réservées au personnel, et celles que les membres de la famille avaient le droit d'accomplir, a fait émerger une dimension plus sociale et plus subjective des visites, et permis de mettre l'accent sur les relations entre les visiteurs et les résidants plutôt qu'entre les visiteurs et les membres du personnel.

D'autres personnes à l'extérieur de l'établissement, en particulier les membres de la famille, offraient également un certain soutien social. Parfois, malgré leurs bonnes intentions, ces autres personnes provoquaient plutôt un certain découragement. Par exemple, une participante s'est sentie insultée après s'être fait dire que ça se passait bien pour elle. Elle aurait aimé voir ces gens à sa place : « Puis il y a des gens qui m'ont dit, « oh he's doing great » et tout ça, mais des fois, ils ne sont pas avec lui, alors ils ne savent pas » (I8, 358-363).

Acquérir une perspective. Pour bien comprendre la dynamique, il faut tenir compte des points de vue des participants durant le temps passé avec leur parent à l'établissement de soins de longue durée. Les participants jouent un rôle dans le processus de deuil, rythment la vie du résidant et créent un « chez-nous ».

Les visiteurs vivent un deuil lorsqu'ils viennent passer du temps à l'établissement de soins de longue durée. Ils doivent accepter le fait que leur parent ne vive plus chez lui; ils doivent s'habituer à le voir changer; et partager avec lui les pertes subies du fait qu'il est maintenant en établissement, ou qu'il souffre d'une maladie chronique. Ils doivent également se préparer à la mort prochaine de leur être cher. Voici comment Joanne exprime son deuil :

Cela nous fait vraiment réaliser à quel point on est chanceux de l'avoir encore avec nous. Vous savez, un jour va venir où nous ne pourrons plus

venir la voir comme ça. Alors j'en profite chaque fois que je viens passer du temps avec elle, sachant que le temps est proche où je regretterai probablement de ne pas l'avoir fait davantage quand je le pouvais (I5, 914-925).

Les visiteurs rythment également la vie du résidant, car le déménagement d'une personne âgée dans un établissement de soins de longue durée exige une adaptation à tout un autre monde, tant pour le résidant que pour la personne qui lui rend visite. Je dirais que c'est par le biais d'une routine et de rites qu'un certain rythme s'instaure et favorise l'adaptation. Diane :

On lui achète des biscuits et des boîtes de kleenex... puis des chips – puis vraiment, ce n'est pas nous autres. Parce que, quand qu'on vient, il aime ça nous offrir de quoi à manger – alors c'est pour nous autres. Puis lui bien, on a de quoi à manger, alors il est content (I7A, 1065-1076).

Ce qui importe, c'est vraiment de garder un lien avec le « monde extérieur ». Les visiteurs assurent cette continuité en leur apportant le journal en langue française (*La Liberté*); en poursuivant les traditions familiales (par ex. : partager un repas, toujours avoir de la nourriture à offrir); en rappelant les faits vécus par la famille (les mariages et les secrets de famille). Cette routine et ces rites qui rythment la vie mettent en lumière les puissants marqueurs culturels des francophones : l'importance de la religion, des liens familiaux, des repas en commun, et du maintien d'un sens de la communauté au sein de l'établissement de soins de longue durée.

Faire d'un établissement de soins de longue durée un endroit où l'on se sente chez soi constitue pour les visiteurs et pour les résidants une entreprise dynamique, et qui se poursuit dans le temps. Il ne suffit pas d'apporter des objets familiers et de se remémorer des souvenirs. La toute première étape de cette entreprise qui consiste à se créer un nouveau chez-soi est d'accepter que l'établissement de soins de longue durée est désormais un milieu de vie, à la fois pour le résidant et pour les personnes qui le visitent.

Les résidants et les visiteurs ont des efforts à fournir pour faire advenir cette acceptation. Comme le disait l'un des participants : « C'est ça, c'est son monde à elle, c'est un nouveau monde. Puis nous autres, il faut l'accepter aussi» (I1, 823-825). Cette acceptation se reflétait dans le langage utilisé par les participants pour décrire l'établissement. Voici comment un visiteur décrit le nouveau « milieu de vie » de sa parente : « Bien, ce n'est pas un hôpital, c'est son chez-eux» (I2, 1092-1093). Cette étude nous fait connaître des visiteurs qui empêchent leur parent d'être complètement coupé du monde extérieur (créent une perméabilité) en venant lui rendre visite souvent, en accompagnant le résidant à son domicile antérieur et dans le voisinage, en échangeant des lettres, en téléphonant et en venant jaser du bon vieux temps avec lui.

Bien que la plupart des participants aient tenté de créer cette atmosphère d'un nouveau chez-soi, ils ne considéraient pas tous avoir réussi. Certains participants disaient se sentir tristes que leur parent ait dû quitter son milieu familial et les biens auxquels il avait mis toute une vie à s'attacher. Bien que les participants se disaient satisfaits de l'établissement où ils effectuaient leurs visites, la plupart déploraient l'idée même de devoir vivre en établissement.

Adoption d'un rôle. La dernière composante de l'expérience de la visite est l'adoption d'un rôle dans le cadre des soins de longue durée. L'adoption de rôles fait partie du comportement humain, et cela nécessite de se distancier soi-même par rapport aux autres. Les visiteurs qui ont fait l'objet de cette étude ont adopté des rôles à caractère social, ont accepté un rôle de surveillant, ont exercé des devoirs et pris des engagements. Pour certains participants, le premier but de leur visite était de nature sociale. Ces derniers avaient de toute évidence reconnu l'importance d'entretenir des liens

permanents. Certaines de ces visites ayant fait l'objet de l'étude se voulaient de nature surtout sociale. En fait, la plupart comportaient une composante sociale même lorsque le but principal de la visite était tout autre.

Pour Jocelyne, rendre visite à sa mère, c'était comme rendre visite à n'importe qui d'autre: « ce n'est pas comme si on devait se forcer pour bavarder, ça vient tout seul» (15,463-464). Les conversations entre Jocelyne et Madeleine portaient souvent sur la vie quotidienne, tout comme les conversations de n'importe quel visiteur avec une autre personne. Ces causeries permettaient d'assurer la continuité et un lien avec le monde extérieur.

D'autres visiteurs s'étaient donné pour mission de superviser la qualité des soins et la qualité de vie du résidant. Les visiteurs qui avaient adopté cette fonction de superviseur n'avaient pas toutes les mêmes motivations pour ce faire. Certains se sentaient coupables du fait qu'ils ne pouvaient plus pourvoir eux-mêmes aux besoins du membre de leur famille au sein de la collectivité, ce qui les portait à s'assurer que le personnel prodiguait les meilleurs soins possibles. D'autres étaient simplement motivés par un sentiment de compassion pour le membre de leur famille. Marc a adopté ce rôle dans un but précis, soit: « S'assurer de son confort. Je pense que c'est la chose la plus simple» (12, 1195-1197).

Certains visiteurs s'engageaient vis-à-vis du résidant simplement par sens du devoir, consécutivement à l'amour qu'ils ressentaient envers leur parent ou à un sentiment de culpabilité. Ce devoir était perçu comme un fardeau à porter. Même s'ils n'y trouvaient plus aucun plaisir dans certains cas, les visiteurs poursuivaient la même routine et répétaient les mêmes rites par sens du devoir et des responsabilités, en tant

qu'enfant adulte ou conjoint. Joanne considérait le temps passé avec sa mère comme un devoir. Elle se sentait responsable d'assurer le bonheur de sa mère et prenait son rôle à cœur :

Ça serait le temps qu'on passe avec ma mère. C'est un temps précieux parce qu'on ne sait pas comment longtemps encore qu'elle sera avec nous, et on va prendre l'occasion de cette journée-là de vivre pour qu'elle soit heureuse pour la journée. Pour moi, c'est une job pour moi de voir que ça va se dérouler bien pour elle dans la journée. Pour moi c'est un devoir, de voir que ma mère est contente... Pour moi, c'est un devoir qu'il faut que je fasse pour ma mère» (14, 1577-1614).

Les conjointes qui ont participé à cette étude, ont joué un rôle d'engagement associé aux soins de longue durée. L'objectif principal de leurs visites était de procurer des soins. Il s'agissait pour eux de continuer à assumer leur rôle d'épouse et de pourvoyeur de soins. Elles participaient plus que jamais aux soins prodigués à leur partenaire. Tout comme la recherche de Ross (1997) l'avait révélé, j'ai constaté que les conjoints ne faisaient pas de distinction entre les tâches techniques et non-techniques, en ce sens qu'ils prodiguaient simplement « des soins ». Dolorès disait venir voir son mari afin de d'assurer qu'on réponde bien aux besoins de celui-ci, et que les soins qu'elle-même et le personnel lui prodiguent soient de bonne qualité : « Je me sens très bien là, je suis contente, parce que je sais qu'il a bien dîné, bien mangé, et puis il est de bonne humeur» (16, 160-162).

Il est important de bien comprendre quels rôles adoptent les visiteurs, car non seulement cela aide-t-il les visiteurs à comprendre leur vécu, mais cela améliore également les relations entre le personnel et les visiteurs et, en bout de ligne, la qualité de vie des résidants.

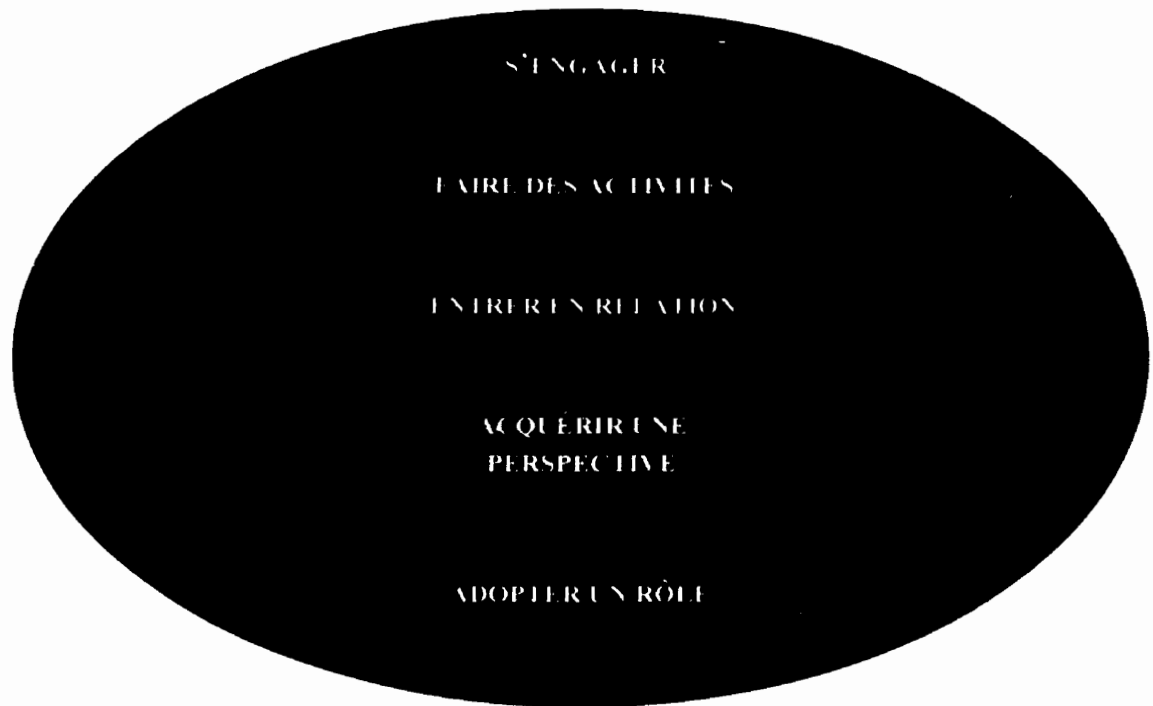
## Synthèse

Les témoignages recueillis me permettent d'avancer que les soins de longue durée signifient : s'engager, faire des activités, entretenir des relations, acquérir une perspective et adopter un rôle. Ces éléments ont servi à structurer les données recueillies et ont suggéré des façons d'organiser les données de manière à la fois conceptuelle et visuelle (voir Figure 1). Cette structure, adaptée de Lorenz Dietz et al. (1994), permet d'organiser les acquis sur cette démarche qu'est la visite en insistant sur le caractère dynamique et ininterrompu de la pratique des visites. Ces composantes constituent les caractéristiques principales nécessaires à la compréhension d'un phénomène social. Les éléments constituent un support sur lequel chaque composante vient s'appuyer. Les ellipses représentent une démarche qui prend corps à partir des caractéristiques émergentes, évolutives et ininterrompues de la vie en groupe. Ils constituent une conceptualisation heuristique du concept de « visite » du fait que l'étude de n'importe laquelle de ces composantes entraîne inévitablement l'examen des autres composantes.

## Résumé et conclusion

Les résultats de cette recherche suggèrent que les visiteurs d'un établissement de soins de longue durée donnent un but et un sens à leurs visites. À l'opposé de ce que l'on retrouve dans plusieurs articles publiés sur le sujet, ces personnes considèrent les visites comme un geste social permettant de prodiguer des soins, de procurer de l'attention aux résidents, et d'entretenir de bonnes relations. Il est clair que le concept de visite est supérieur à la somme de ses éléments et constitue une façon d'être.

Figure 1. Diagramme conceptuel





En résumé, cette étude a servi à définir la visite dans un établissement de soins de longue durée et à déterminer quels en sont les composantes et les éléments. Elle ajoute à la rare documentation existante sur le sujet et fournit un pendant aux études orientées vers les problèmes et la pathologie. Plus important encore, elle enrichit la somme de renseignements limités dont nous disposons sur la dimension subjective des visites, et les relations qu'entretiennent les Franco-Manitobains avec les membres vieillissants de leur famille. Enfin, elle répond au besoin relevé par Dupuis et Norris (1997) de se pencher sur la dimension subjective, soit le sens, les attentes et les comportements relatifs aux visites effectuées par les membres d'une famille engagés dans les soins de longue durée.

## CHAPTER 1

### Introduction

Visiting a family member in a long-term care setting may be considered a prerequisite for caregiving or simply a form of social interaction (Minichiello, 1989; Ross, 1997). Nonetheless, visiting has been identified as the most important aspect of caring for a family member in long-term care (Ross, 1997). The maintenance of family ties is essential to the quality of life for residents as it enhances life satisfaction, morale, and sense of personal control (Arling, Harkins, & Capitman, 1986; Greene & Monahan, 1982; Harel & Noelker, 1982). The purpose of this thesis was to explore the visiting experiences of family members who visit kin in a long-term care setting. The literature on the institutionalization of the aged focuses primarily on the predictors of placement, the issues associated with the decision-making process, the transition period, and family involvement within the institution (Naleppa, 1996). Less attention has been paid to the subjective attitudes and the meaning of problems and experiences involved in visiting an elderly relative in long-term care (Gubrium & Sankar, 1994).

Canadian research specifically examining how families remain involved in the lives of their elderly relatives after placement in a long-term care facility is minimal. Furthermore, the experiences of Franco-Manitobans in the care of their aged members have not been addressed although ethnicity and its impact on the family support system has emerged as an area of interest in gerontology (Driedger & Chappell, 1987). Therefore, I proposed a study to explore the involvement of Franco-Manitoban families in the lives of their institutionalized elderly relatives. Specifically, the study addressed the visiting experiences of family members who visit relatives in long-term care.

### Exploring Life in Long-Term Care

Several factors influenced my desire to study life in the long-term care setting. First, I had a strong interest in the lived experiences of residents in these institutions and their families. Furthermore, I believed that with a rapidly aging population, it was worthwhile to examine and understand lived experiences in such facilities. Finally, findings in the area of family involvement were varied and often contradictory and minimal research focused on the experience of Francophones.

#### Lived Experiences

I trace my interest in the topic of visiting to my own personal experience as an employee in a long-term care setting and as a visitor in such a facility. As an employee, I developed an interest in better understanding the experiences of residents in long-term care and their families. Personal reasons, namely the experiences of my grandparents who were residents in a long-term care facility also motivated me. However, the real desire to explore life in long-term care was instigated when a visitor entered a facility where I was employed and noted in amazement: “this is a busy place — almost like a small city!” This comment made me realize that life in long-term care was quite different from life in a hospital setting or life at home. I remained puzzled as to the significance of visits, how they worked, and their wider social import.

#### Demographics

As our population of seniors continues to increase, I feel a sense of urgency to better understand this world. In the context of demographic projections, the experiences of family members whose relatives are institutionalized are of particular importance (Brody, Dempsey, & Pruchno, 1990). It has been estimated that approximately 25% of

the aged will spend at least some portion of their later years in an institutional setting (Forbes, Jackson, & Kraus, 1987). According to the Centre on Aging (1996) there were 8,681 individuals living in 122 personal care homes in Manitoba during 1995. This number represented only 5.4% of Manitobans aged 65 and over. Most others lived in the community. With advancing age, however, the proportion of elderly in long-term care increases rapidly to approximately 40% among seniors aged 85 and over. In Manitoba, over one-half (52.8%) of Manitobans aged 95 to 99 and 63.9% of those aged 100 and over lived in institutions. Statistics Canada has projected that there will be almost 1.6 million Canadians aged 85 and over in 2041, a number more than four times greater than the figure in 1995. The rapid increase in the number of people in the oldest age groups in the next few decades underlined the need to better understand life in long-term care settings (Ross, 1997). Ross (1997) acknowledged that "institutionalization will continue to be necessary for a considerable number of older persons despite a general trend away from institutional care" (p. 52). In light of these demographic factors, a study that addressed the experiences of visitors in long-term care institutions was timely.

#### Family Involvement in Long-Term Care Settings

In Canada, informal caregivers play an important role in the health care system. According to the National Advisory Council on Aging (1999) informal caregivers provide about 80% of all home care to seniors living in the community and up to 30% of services to seniors living in institutions. Dupuis and Norris (1997) identified numerous terms used to describe family involvement in the long-term care setting, such as "visitor" (Greene & Monahan, 1982; Hook, Sobal, & Oak, 1982; Minichiello, 1989), "ally" (Campbell & Linc, 1996), "resource" (Rubin & Shuttlesworth, 1983), "quasi monitor"

(Schwartz & Vogel, 1990), “adjunct staff” (Coen Buckwalter & Richards Hall, 1987), “caregiver” (Dellasega, 1991; Grau, Teresi, & Chandler, 1996), and “client” (Montgomery, 1982; Pratt, Schmall, Wright, & Hare, 1987). Hence, it is clear that family members perceive themselves and are perceived by others in various ways in long-term care settings. No particular term is used consistently to describe family members’ involvement.

To address such variations, Gubrium (1995) has argued for a “deconstructive examination of the taken-for-granted language of caregiving, of the concepts and related objects of research that are assumed to specify what the research is all about in the first place” (p. 268). In essence, a critical examination of the term “caregiving” is required. It was clear that research on caregiving was extensive, diverse, even contradictory (Gubrium, 1995). Consequently, this study addressed the visiting experience of family members thereby deconstructing what some call “caregiving”. To deconstruct the concept of caregiving requires an examination of the experiences of visitors to describe what they actually do in long-term care and the meaning they attach to their experiences.

In a Canadian study regarding spousal caregiving in long-term care institutions, Ross (1997) found that visiting was a prerequisite to task performance and that wives perceived visiting as the most important aspect of their caring. Interestingly, wives considered visiting as a task itself and not simply as the context within which other tasks were performed. A weakness of role expectation studies was identified when Ross (1997) found that care-related activities, performed by spouses, extended beyond the usual list of tasks used in studies of role expectations (Rubin & Shuttlesworth, 1983; Schwartz & Vogel, 1990; Shuttlesworth, Rubin, & Duffy, 1982). She concluded that

using a list of pre-selected tasks would not have uncovered the visiting component of caring. Interestingly, the findings not only described the tasks that wives performed but also the purpose and rationale for them being there. On the basis of Ross' (1997) findings, this study was undertaken to further explore the "visiting" aspect of caring which spouses found so crucial, as well as the subjective attitudes and the meaning of experiences involved in visiting. Equally important was to extend the focus beyond spouses to include other relatives such as adult children who have been found to have different experiences than spouses (Grau et al., 1996).

### Francophone Literature

Very little Canadian research exists which specifically examines how families remain involved in the lives of their elderly relatives after placement in a long-term care facility. Furthermore, the experiences of Franco-Manitobans in the care of their aged members have not been addressed. Woodward (1994) compiled a document examining the French-language literature on social support in Canada. He concluded that social support for the elderly is an area more widely researched by Anglophone scholars than Francophone. French-language literature exists on the topic, but it refers largely to English-language studies. Woodward (1994) also indicated that the French-language literature on social support takes a different focus than the English. For example, Anglophone researchers consider social support as informal support for the elderly person in need of aid, whereas the French literature often approaches social support as informal or formal support for the caregiver of the person in need of aid (Cossette, Lévesque, & Laurin, 1995; Ducharme, 1987; Ducharme, 1991; Marchand, Béland, & Renaud, 1994). Most of these studies were conducted with informal caregivers in the community.

One study conducted by Marchand, Béland, and Renaud (1994) in Québec specifically examined informal caregiving in institutional settings and the burden that caregivers experience. The sample included 197 caregivers of parents living in long-term care. In this sample, 45.8% were from the Montréal and Québec regions and 54.2% from the rest of the province. In another study, Renaud (1987) estimated that 1.9% of Québécois helped their aged parent in an institutionalized setting. Renaud (1987) concluded that family members generally have a lower level of involvement in long-term care as compared to the community and the institution provides most of the care. In the study by Marchand et al. (1994), it was concluded that objective burden was not as high as subjective burden in the institutional setting. In essence, the caregivers' perception of their parents' autonomy, the social support available to caregivers, help for bathing and other activities of daily living were all factors that could heighten or diminish the burden felt by caregivers. It is evident that the study of informal helpers in long-term care is in its early stages (Marchand et al., 1994).

Although Québécois and Franco-Manitobans share a common language some cultural differences exist (Coutu-Wakulczyk, Bechingham, & Moreau, 1998). Consequently, it is essential to turn to some Franco-Manitoban studies to highlight the experience of Francophones in Manitoba. Some studies have been conducted in Manitoba to specifically address the experiences of Franco-Manitobans. Lahaie (1998) conducted an extensive literature review and found only a handful of studies in the health literature regarding the culture, beliefs, and traditions of Franco-Manitobans (Action Research Consortium, 1995; Comité ad hoc des personnes handicapées francophones, 1993; Gagné, 1995; Lahaie, 1998; Proteau, 1989; Rajotte, 1989). He concluded that most

Franco-Manitoban studies dealt with the identification of needs and access to services. Lahaie's study on the experience of hospitalization of adult Franco-Manitobans is of direct importance to this study. Interestingly, his sample consisted of Franco-Manitobans between the ages of 54 and 88; most of the participants in the sample were elderly persons. The findings of his ethnographic study revealed that a range of factors related to language, family, community, spirituality, and the illness process influenced the experience of hospitalization.

Given the paucity of research on the experiences of Franco-Manitobans in the health care field, an aging population and a need to better understand the visiting experiences, I proposed a study to address these issues. All these factors pointed to a need to better understand the experiences of Franco-Manitoban family members in long-term care settings.

#### Purpose of Study

The purpose of this ethnographic study was to better understand the experience of visiting a family member in long-term care and what influences that experience. Minimal research has been conducted in Canada to examine family involvement in long-term care settings (Dawson, 1996; Gladstone, 1995a; Gladstone, 1995b; Marchand et al., 1994; Ross, 1997). Understanding the family member's perception of visiting is important in determining what constitutes a positive or a negative visit and what influences the experience of visitors in the institutional setting. Moreover, in Manitoba, no literature existed to describe the particular experiences of Franco-Manitobans in long-term care settings. Exploring the cultural behaviour of Franco-Manitobans in a long-term care setting is important as ethnicity is known to have an impact on the care of the aged. This



study helped to fill the gap in our knowledge by exploring the experiences of family members who visited kin in institutions, contributed to our understanding of the major factors that affected visiting in long-term care facilities, and provided insight to the experiences of Franco-Manitoban visitors.

### Significance of Study

It is important to better understand the significance of visiting relatives in long-term care as their visits affect quality of care and quality of life for both staff and residents. Linsk, Miller, Pflaum, and Ortigara-Vicik (1988) explained that “designing partnership programs to engage families and institutions was a challenge to the long-term care field and a promising solution to the problem of achieving continuity of service among home, community, and the health care institution” (p. 120).

Exploring the visiting of family members in long-term care settings by kin is an area of significant policy relevance given its implications for the quality of life of residents (Minichiello, 1989). As well, family involvement is important given that the majority of residents will likely remain in long-term care for the rest of their lives (Doobov & McCusker, 1986; Howe, 1983). Understanding the visiting experience represents “an important topic which should be associated with research on institutional care” (Minichiello, 1989, p. 260). In order to expand our knowledge of this topic, this study:

- Examined what visitors actually did when they visited.
- Identified the opportunities and challenges experienced by visitors who visited kin in long-term care.

- Provided a better understanding of the specific experiences of Franco-Manitobans who visit kin in a long-term care setting.
- Determined whether visitors differentiated between visiting and caregiving.
- Examined the implications for policy and practice.

### Research Questions

In order to understand family involvement, it was critical to understand family members' visiting experiences and how they perceived their visits in the long-term care setting. The following questions were examined in this study:

- What is visiting?
- What are its functions, components and elements?
- What are the subjective dynamics of the visiting experience?
- What form does visiting take in a Franco-Manitoban context?
- What is the relationship between visiting and caregiving?

### Theoretical Orientation

Symbolic interactionism (SI) guided this study, which examined how visitors constructed meanings in the visiting experience. Several underlying assumptions informed by the philosophical world view of symbolic interactionism guided the research process. It provided direction to reveal how actors interpreted events and situations. It also provided direction to generate a better understanding of the visiting experience from an interpretation of the stories shared by participants. Furthermore, the theory was useful to understand the subjective experiences of actors, in this case visitors, within the context of objective reality (Zimmerman, 1995). LaRossa and Reitzes (1993) maintained that SI focuses on the "connection between symbols (i.e. shared meanings) and interactions (i.e.

verbal and nonverbal actions and communications)” (p. 135). Moreover, SI provided a “frame of reference for understanding how humans, in concert with one another, create symbolic worlds and how these worlds, in turn, shape human behavior” (LaRossa & Reitzes, 1993, p. 136).

There were several reasons for using SI as a conceptual framework for this study. This orientation was useful because of its focus on objective and subjective reality (Ross, 1997). As well, it “insists upon rigorously grounding its notions of the ways in which human group life is accomplished in the day-to-day practices and experiences of people” (Prus, 1996, p. 10). Some researchers have maintained that SI has had more of an impact on the study of the family than any other theoretical perspective (LaRossa & Reitzes, 1993). Hence, it lent itself well as an orientation for studying the visiting experiences of family members who visited kin in long-term care. SI focuses on the process by which meanings are constructed through interaction with both the environment and other people. This theoretical perspective pays particular attention to the acquisition and generation of meaning. Thus, SI was helpful in understanding how visitors created meanings that helped them make sense of this part of their world. SI also assumes that actors think about and act according to the meanings they attribute to their actions and context. In viewing visiting as a “social process characterized by activities and feelings and imbued with meanings that evolve as a result of the circumstances of visitors, residents and others in their social world” (Ross, 1997, p. 56), SI was a useful theoretical framework.

Some researchers have used interpretative perspectives such as SI to examine life in long-term care settings. In a review article, Dupuis and Norris (1997) suggested the use of SI for the study of family involvement in long-term care because it was possible to

link meaning, expectation and behavior. Ross (1997) utilized the interactionist perspective in sociology to study spousal caregiving in the long-term care setting. Gubrium and Sankar (1994) also used an interactionist perspective to study numerous aspects of family involvement both in the community and the long-term care setting. Hence, SI was an appropriate philosophical orientation for this study.

### Summary

Exploring the visiting experiences of family members who visited kin in a long-term care setting was the purpose of this study. Increasing our understanding of lived experiences made a useful contribution to the literature on family involvement in long-term care. The study, informed by symbolic interactionism, examined how families construct meanings in the visiting experience.

## CHAPTER 2

### Literature Review

Family involvement is recognized as a critical issue in gerontology and is studied from various perspectives (Blieszner & Hilkevitch Bedford, 1995). Most gerontological research focuses on family involvement in the community, where the majority of elderly persons reside. The research specific to family involvement in the institutional setting is less extensive. However, the existing institution-based research does address issues such as the placement decision, the transition period and the family-staff relationships. These studies have been instrumental in identifying the various issues encountered by families in long-term care settings. Salient research on these topics is reviewed in subsequent sections. Various theoretical frameworks and research designs applied to the study of family involvement in long-term care settings are also examined. In addition, gaps in the literature are identified. In order to understand family involvement in long-term care settings, Dupuis and Norris (1997) pointed out the importance of understanding and considering family members' experiences, and how they perceive their involvement in the immediate setting in which they find themselves to better understand family involvement in long-term care. Hence, the following literature review develops from this perception.

#### Significance of Visiting in Long-Term Care

The literature review on visiting experiences in long-term care is for the most part limited. Most studies had little to offer in the way of a sustained analysis of the essentials of visiting or the forms and functions of visiting. Some self-help books focused on quality visiting and long-term care facilities to help visitors make their experiences satisfying, meaningful and enjoyable (Thompson, 1987). These books contain ideas,

suggestions for activities and discussions on the many factors that affect the quality of life for all concerned.

Although visits can be therapeutic for elderly residents, they can be stressful for family members (Campbell & Linc, 1996). Assuming that visitation is beneficial, we need to further examine the nature and extent of contacts in long-term care (Hook et al., 1982). Various experiments introducing volunteer visitors and companions to long-term care residents have found a positive relationship between social interaction and personal well-being (Hook et al., 1982). It has been well documented that family involvement is important, almost essential in long-term care. Campbell and Linc (1996) indicated that a great deal of literature is available on the needs of institutionalized older adults, but a minimal amount of research focuses on the needs of the family. This may occur because of a common assumption that family involvement ends when older relatives are institutionalized (Tobin, 1995).

The studies examining the importance of visiting mostly deal with issues related to residents. Less attention is paid to the significance and meaning of visiting for the family member. For instance, several researchers have identified that maintaining ties with family and friends is beneficial to the quality of life of residents. The maintenance of family ties has been found to enhance life satisfaction, morale, and sense of personal control for residents (Arling et al., 1986; Greene & Monahan, 1982; Harel & Noelker, 1982). Furthermore, Ross (1997) acknowledged that the tasks performed by wives helped to maintain their husbands' personal integrity, uniqueness and feelings of self-worth. In essence, family involvement is important for residents of long-term care facilities as it provides a "vehicle for the continuation of relationships"(Ross, 1997, p. 67).

Family members on the other hand may not find visiting as rewarding. Numerous studies have indicated that family members often experience feelings of guilt, depression, demoralization, and stress in long-term care settings.

It is evident that negativity often surrounds the institutionalization of an elderly family member. For instance, Matthiesen (1989) indicated that our society views placement in long-term care as a deviant act. Smith and Bengtson (1979) acknowledged that "long term institutional care for the elderly is associated with many negative images. Of these, perhaps none is more pervasive than institutionalization representing the failure of family support to an aged member" (p. 439). It is true that institutionalization is not always easy. The negativity surrounding institutionalization increases the difficulties and challenges experienced by family members who spend time with their relative.

Family members often experience strong feelings when institutionalization occurs. Depression, loss and guilt have been identified by several researchers as feelings engendered by placing a relative in long-term care. Brody, Dempsey, and Pruchno (1990) for instance conducted a study of 331 adult children whose parents were residents in a long-term care facility and found that predictors of depression for adult children included poor health, competing demands, and lack of involvement with instrumental activities of daily living (IADL) tasks. Sons and daughters in poorer health were more likely to experience depression. As well, competing demands and time pressures related to parent care were linked to depression. Interestingly, assistance with tasks in the long-term care setting was found to have some positive value for daughters because as they performed more tasks they were less depressed. Brody, Dempsey, and Pruchno (1990) suggested that providing assistance with instrumental activities of daily living (IADLs) might have

positive effects for the adult children. It may be that adult children continue to fulfill their responsibility; helping their parents offsets the feelings of guilt experienced by adult children when parents are institutionalized. Emotional effects experienced by adult children appeared in the form of distress about the long-term care facility, such as the care received by the parent, inadequate numbers of staff and their availability, and the staff's attitudes toward parent and adult children. Brody et al. concluded that various features of the long-term care environment have direct consequences for adult children. Hence, attention should be drawn to the implications for long-term care policies and procedures to address such issues.

To examine demoralization, Grau, Teresi, and Chandler (1996) conducted a study among sons, daughters, spouses and other relatives of nursing home residents (N=422). Predictors of demoralization included guilt and worry about placement, caregiver burden, and poor physical health. Spouses were found to be the most vulnerable group because they experienced the highest demoralization. Caregiving-related factors had the greatest impact on demoralization. In light of these findings, Grau et al. stated that "the role personal care homes should play in the assessment, referral, or treatment of family members warrants further study and inclusion in the health care policy debate" (p. 343).

Guilt and grief have also been found to affect family members. In a qualitative study, Matthiesen (1989) examined the emotional impact on 32 adult daughters of mothers in long-term care settings. Guilt and grief were two psychological themes that emerged following long-term care placement. Matthiesen (1989) indicated that daughters perceived long-term care settings as foreign environments where they needed to learn what went on and what to expect in such a setting. She also found that daughters suffered



in silence. They expressed feelings of isolation and felt the greater community did not understand or care about their situation.

Bowman, Mukherjee, and Fortinsky (1998) conducted a study to examine the differences between community and personal care home caregivers. They concluded that personal care home placement did not prevent strain on family members. The limited amount of research comparing family members of long-term care facilities to community-dwelling elderly has generally reached the conclusion that institutionalization is not a panacea for families (Dellasega, 1991; Pratt et al., 1987; Stephens, Kinney, & Ogrocki, 1991). Bowman et al.'s study included 581 caregivers and compared caregiver strain and its correlates for family caregivers of community and personal care home residents. Family members in the personal care home context reported caregiving to be "just as draining of personal resources, just as intrusive on their lives, and just as emotionally disturbing as those of community-dwelling relatives" (p. 387). Strain for family members was present regardless of the elder's place of residence. In essence, Bowman et al. concluded that families are just as important in the long-term care setting as in the community. Most family members in their study did not view themselves as any less central in helping. They identified themselves as primary sources of assistance and reported extensive involvement in their relatives' care. Staff need to work with families to "determine how to make the most of this involvement" (Bowman et al., 1998, p. 389).

These findings suggest that institutionalization of an elderly relative is not a viable strategy for relieving stress on family members. Many studies have shown that stress does, in fact, continue after institutionalization and placement is not a panacea for most families. Dellasega (1991) examined the stress experienced by community caregivers and

institution-based caregivers in a convenience sample of 124 caregivers. She concluded that ending caregiver stress is not a realistic outcome of institutionalization.

These various studies point to several challenges experienced by family members who visit an elderly relative in long-term care. The difficulties that arise make visiting a challenge.

### Factors Influencing Visiting Patterns

Maintaining ties and continued family involvement are viewed as essential components in long-term care settings. However, the numerous factors influencing visiting patterns make it difficult to understand how ties are maintained and how family members continue to be involved in the lives of the elderly. Some studies on institutionalization have specifically examined visiting in long-term care (Hook et al., 1982; Minichiello, 1989; Thompson, 1987). Much of this literature focuses on the frequency of contacts and the factors that influence which people are more likely to visit and why. A limited amount of research examines the actual visiting experience of family members in the institutional setting or the meaning attached to their experiences. The negativity surrounding the initial involvement, the characteristics of residents, visitors and the long-term care environment will be discussed in the following section.

### Involvement in Long-Term Care Settings

The initial involvement in long-term care is often surrounded by negativity. First, institutionalization of an elderly family member is often thought to be a last resort. It is generally undertaken when all other avenues have been exhausted and when family members are no longer able to cope with the burden (Matthiesen, 1989; Pruchno, Michael, & Potashnik, 1990). As a consequence, the placement of an elderly person in a

long-term care facility is often thought to be the termination of family involvement, where family members relinquish all their duties to the institution (Bowers, 1988). Another myth presupposes that families abandon their aging members in institutions (Smith & Bengtson, 1979). Notwithstanding these perceptions, numerous studies on family involvement in long-term care have addressed the continuation of family relationships after institutional placement (Montgomery, 1982; Smith & Bengtson, 1979; Stull, Cosbey, Bowman, & McNutt, 1997). Research has demonstrated that family members have continued contact and close emotional ties with elderly relatives admitted to long-term care facilities (Bowers, 1988; Smith & Bengtson, 1979). The reverse is also true, where strained family relationships are likely to continue to be so after institutionalization (Smith & Bengtson, 1979). The difficulties experienced by family members in the placement process often create negativity surrounding institutionalization as a whole. The above make the initial involvement as well as visiting all the more difficult.

An Australian study by Kellett (1999) underlines this continued involvement. One of the major themes identified in her study was that of searching for new possibilities to continue family caring. Family members felt duty-bound to focus on establishing possibilities for human connection. They possessed special knowledge and skills, provided the personal approach, acted as advocates, lived with hope of improvement and recovery, felt satisfied when care experienced was deemed to be quality care and possessed a sense of worth through making a useful and positive contribution. This study offers a perspective whereby it is possible to begin to understand the meaning attached to the experience in long-term care.

### Characteristics of Residents and Visitors

Studies have explored the characteristics of visitors and residents to determine which factors affect the frequency of visiting. It is evident that a gamut of factors affect the frequency of visiting in long-term care. First, the availability of people who are willing and who can visit influenced visiting frequency in Minichiello's (1989) study. Studies suggest that residential propinquity, that is, how close people live to one another, is an important predictor of frequency of visiting (Greene & Monahan, 1982; Hook et al., 1982; Minichiello, 1989). Although there have been some contradictory findings, the length of time a resident has spent in long-term care may also affect the frequency of visits (Greene & Monahan, 1982; Minichiello, 1989). According to Hook (1982) and Montgomery (1982) frequency of visits was negatively associated with length of residence in long-term care. Montgomery's (1982) results may have been biased because a large sample of residents had severe dementia and had lived in long-term care for many years. In this case, poor physical and mental health may discourage visitors thereby decreasing the frequency of visits over time. Hook's (1982) study is also limited because it was conducted over a two-week period; thus family members who did not visit during that time were not included. On the other hand, Greene and Mohanan's (1982) study as well as Minichiello's (1989) found that families maintained contact with the elderly without a significant decline over time. However, Minichiello's (1989) work was biased towards residents without severe physical or mental impairments which could inhibit communications.

The attributes of residents and visitors also have an effect on the interaction between them. For example, differences exist between the social ties of men and women (Minichiello, 1989). Women generally have larger social networks, provide and receive more support from their children, and develop more expressive relationships than men (Minichiello, 1989). Consequently, this may have an effect on the time spent visiting and the nature of the visit.

Some researchers have questioned whether physical or cognitive impairments of residents influence visiting patterns. For instance, cognitive and physical impairments may inhibit communication or make the visit too difficult for visitors. Greene and Mohanan (1982) found a positive relationship between level of activities of daily living (ADL) impairment and frequency of visits. The findings suggest that visitors do not find ADL impairments difficult to confront. The degree of psychosocial impairment was not a significant predictor of visitation. However, Minichiello (1989) stated that the health of residents as well as how others perceive them may affect visiting.

The visitor's attributes are also important to the visiting patterns. For example, it has been found the health of the visitor may be a barrier to visiting especially for spouses who may also be suffering from poor health. Competing demands were also thought to inhibit visiting, however, in Minichiello's (1989) study they were not found to be significant. Finally, visiting may be influenced by the quality of the relationship prior to institutionalization. Minichiello found that the resident's perceived quality of the relationship and visiting frequency were strongly related. Good relationships were predictors of visitation and people who found the interaction rewarding were more likely to visit.

### Features of the Long-Term Care Setting

Kahana, Kahana, and Young (1985) stated that the presence of visitors can decrease the overall institutional atmosphere of a long-term care facility. However, numerous studies have concluded that effects of institutions can inhibit interactions between visitors and residents (Minichiello, 1989). Montgomery (1982) found that personal care homes, which do not include families and friends in activities and have limited visiting hours receive visitors less frequently.

Long-term care facilities are definitely a "world of their own", involving a gamut of personalities, including those of residents, family members, staff, and volunteers. Savishinsky (1991) treated long-term care facilities as microcosms of the culture and the people within the institution. Many individuals are involved in the daily life of residents and all have their professional discourse. Residents and families often do not share the symbols of communication and conceptions of reality that are peculiar to these groups. They must learn the language and assumptions of the culture before they feel secure in the long-term care facility. It is likely that some may never achieve this security. The social organization of long-term care facilities is complex, yet must be studied because it organizes and shapes the lives of residents and families.

A limited amount of research has examined how institutional care policies influence family integration in the long-term care setting (Minichiello, 1989; Montgomery, 1982). Contradictory evidence has been found; some researchers have concluded that policies have minimal influence on family integration and others have found that policies can have a positive outcome for family relations. For example, Montgomery (1982) found a strong relationship between policies and family integration,

however, Minichiello (1989) concluded that the influence of the long-term care environment on family integration was significantly related to the frequency of visitation, but its correlative was not as high as one would expect.

These various factors influence the visiting patterns in different ways and many questions remain to be answered because of the varied and often contradictory findings. In light of these many factors, Gubrium (1987) concluded that "long-term care, as opposed to short term care, serves to routinize, ramify and confound organizational and family ties. It is not that the family is dissolved into organizational contingencies in the long run, but that familial experience engages the organization time and apparatus sufficient to diffuse it far beyond its conventional domain as a social form" (p. 40).

#### Nature of Visits

The nature and extent of the contacts that occur between the elderly in long-term care and visitors is not well understood (Hook et al., 1982). A limited amount of research specifically addresses what family members actually do when they visit (Dupuis & Norris, 1997).

The most widely utilized framework for examining family involvement in long-term care is Litwak's structural-functionalist framework — the theory of shared functions and balanced coordination (Dupuis & Norris, 1997). The advantage of using such a framework is that it recognizes the importance of both formal and informal supports necessary for optimal care of residents. However, this task-assignment framework provides a limited understanding of family involvement in long-term care. Being involved is more than simply performing tasks for the resident. The perceptions of visitors in this particular setting need to be understood. Most studies examining family

involvement have utilized a predetermined list of tasks and have explored family members or staff expectations regarding the tasks family members should perform.

Using Litwak's (1981) theory, researchers have found that a division of labor occurs between families and staff, such that each accepts responsibility for different domains of care. According to the theory, formal and informal providers assume tasks that suit them best. Staff are responsible for technical tasks such as medical care and aspects of security, housekeeping, and cooking while families are responsible for nontechnical tasks such as those involving idiosyncratic needs in areas of personalized room furnishings, leisure-time activities, clothing and special foods (Rubin & Shuttlesworth, 1983; Shuttlesworth et al., 1982).

However, qualitative studies have found that wives did not discriminate between technical and non-technical tasks (Ross, 1997). They felt responsible for performing any tasks required by their husbands. These findings contradict studies that describe a division of technical and non-technical care where families are responsible for the emotional care rather than tasks involving physical or material needs. Bowers' (1988) work supports the view that families do not discriminate among tasks and provide both physical and emotional care.

It is not sufficient to consider only the tasks family members perform; the meaning in the context of different social interactions and ever-changing circumstances must be examined as well (Dupuis & Norris, 1997). As stated by Blumer (1969), "the situation and meaning of the situation for the family member is continually defined and re-defined through interaction with "others", both within and outside of the immediate situation, and through a complex "process of interpretation" (p. 5). It is therefore



essential to consider the meaning attached to the visiting experiences of family members in order to understand their perspective.

### Culture and Aging Families

When examining culture and aging, it is useful to turn to the concepts of language, relationships, family and spirituality. It is well known that maintaining the French language has been a struggle for Franco-Manitobans. It often depends on the strength of the local French community (Coutu-Wakulczyk et al., 1998). Hence, a long-term care institution, which serves the Francophone population of Manitoba in their language of choice, is of particular importance. Much of the literature on Franco-Manitobans emphasizes the struggles to preserve the French language and the culture. Few studies have dealt with the relationship that Franco-Manitobans have with their aging family members. Although little has been written on these relationships, we know that French-speaking Canadians differ from English-speaking in several ways discussed in this section.

Researchers have recognized the importance of taking cultural factors into consideration when exploring the lives of elderly persons (Driedger & Chappell, 1987). In Manitoba, approximately 50,000 people or 5% of the population identify French as their first language (Chartier, 1998). Seniors, 65 years and older, make up a larger proportion of the Winnipeg Francophone population (18%) compared to the overall population of Winnipeg (14%) (Winnipeg Regional Health Authority, 2000). The Francophone population is also aging as is the general population.

A classic definition of culture found in the *Modern Dictionary of Sociology* is "that complex whole which includes knowledge, belief, art, morals, law, custom, and any

other capabilities and habits acquired by man as a member of society” (Theodorson & Theodorson, 1979). Furthermore, “culture consists of patterns, explicit and implicit, of and for behavior acquired and transmitted by symbols, constituting the distinctive achievements of human groups, including their embodiments in artifacts; the essential core of culture consists of traditional (i.e., historically derived and selected) ideas and especially their attached values” (Theodorson & Theodorson, 1979). According to symbolic interactionists, the essence of culture is language and symbols. From this perspective, culture consists of systems of human meaning. This view is particularly useful for this study as its focus is useful in understanding the visiting experiences of Franco-Manitobans who visit family members in long-term care settings.

Coutu-Wakulczyk et al. (1998) stated that “spatial distancing for French-speaking Canadians differs among family members, close friends, and the public. When in the intimacy zone, people may touch frequently and converse in close physical space; however, they tend to avoid physical contact in the public arena. When greeting another person, men usually shake hands. Close female friends and family members may greet each other with an embrace. When receiving intimate care, many women tend to be modest, especially the elderly. The health-care provider needs to respect their modesty and provide privacy when delivering physical care” (p. 279). Coutu-Wakulczyk et al. conclude that “many elderly with a strong religious background maintain a future worldview regarding life after death and a past orientation celebrating death anniversaries of family members and other events. However, many of the younger generation reject past traditions and attempt to balance enjoying the present and working and planning for their future” (p. 289).

Coutu-Wakulczyk et al. (1998) stated that “French-speaking Canadian family membership is known for its closeness and some families are a “closed” family system. Within the microcosm of the French Canadian population, the physical and social quality of the microenvironment is more critical to health and survival than wealth and a mechanical connection” (p. 282). A study by House, Lanais, and Umberson (1988) reported widespread and strong correlations between mortality and social support networks and concluded that friends and family keep French Canadians alive. Evans (1994) further supports this notion by indicating that the sheer number of contact persons one has is protective, regardless of the nature of the interaction.

Coutu-Wakulczyk et al.(1998) described older adult generations as more inclined to use prayers for finding strength and adapting to difficult physical, psychological, and social health problems. In times of illness and tragedy, French-speaking Canadians use prayer to help recovery. However, many of the younger generation are not strongly influenced by religious values and beliefs and faith practices.

Regarding actual visiting, Coutu-Wakulczyk et al. (1998) pointed out that “for hard-working men and women of previous generations, leisure activity was a trivial expression. The little time that could be spared on holidays was dedicated to visiting distant relatives” (p. 289). These findings on French Canadians apply to this work as they provide a base upon which to build knowledge of this culture.

### Summary

A number of different approaches have been taken to explore life in long-term care settings. However, the literature specifically relating to the visiting experience is limited, varied and often contradictory. It is evident that visits are influenced by a variety

of factors and that the current research points to a need to better understand the nature of the visiting experience. Another important dimension is that of culture and aging and its impact on the visiting experiences of Franco-Manitobans.

## CHAPTER 3

### Study Design

The purpose of this study was to explore the visiting experience of family members in long-term care from the perspective of visitors themselves. A qualitative approach to the inquiry was considered the most appropriate means of better understanding the perspectives, practices, dilemmas, and interchanges of visitors in long-term care settings. The qualitative design of this study draws specifically on the tenets of ethnographic research. Such a research design provides an “exceptionally rich and viable means of uncovering insights into people’s lived experiences” (Prus, 1996, p. 394). Indeed, ethnographic research attends to the interpretive and interactive dimensions, and to the intersubjective features of human group life. The ethnographic research design used to select participants, and collect and analyze data is described below. Following this, the concept of rigour in qualitative studies and ethical considerations are discussed.

#### Ethnographic Research Design

The method selected for this study was ethnography as it aims to describe and interpret a cultural and social group (Creswell, 1998). Ethnography is an approach used to study social processes and has been used in many classic studies such as Whyte’s (1943) “Street Corner Society” and Goffman’s (1961) “Asylums.” Ethnographic inquiry pays careful attention to the participant’s emic view of the world and to etic insight, that is, why people do what they do or believe as they do.

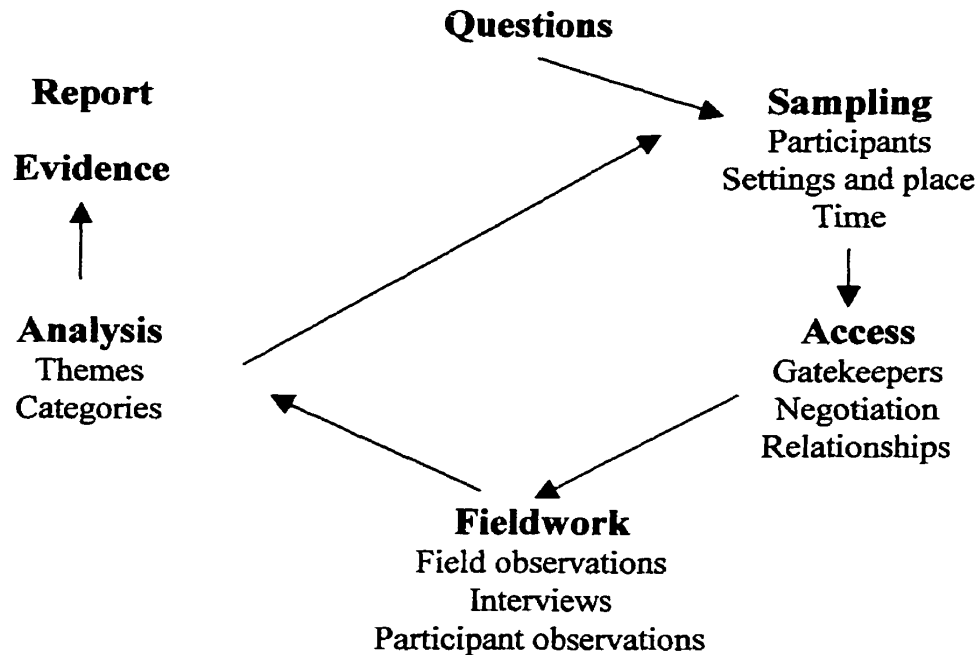
In keeping with Gubrium’s (1995) statement that “we need to take stock of where we have been to move in directions that will lead to the discovery of new meanings and uncover fruitful understandings” and stop “second-guessing” the lived experiences of

participants, the specific method of inquiry used was focused ethnography (p. 267). This style of ethnography provides a close-up view of a group of people who share similar social and cultural characteristics (Boyle, 1994; Germain, 1986). Roper and Shapira (2000) suggested that “because the intent of a focused ethnography is to concentrate efforts on very specific questions, the research can most likely be accomplished within a shorter time than traditional ethnographies” (p.7). Focused ethnographies retain the characteristics of traditional ethnographic inquiries; both are committed to conducting participant observations within the naturalistic setting and asking questions to learn what is happening to gain as complete an understanding as possible of people, places, and events of interest (Roper & Shapira, 2000).

Ethnographic studies assuming an interactionist approach tend to focus most specifically on activities, that is the ways in which people do things and work things out with others (Lorenz Dietz, Prus, & Shaffir, 1994). The central emphasis is therefore on process, or more precisely, on depicting the social processes characterizing people’s practices in a sub-cultural setting. Thus, researchers strive for highly detailed accounts of how people view their life-situations, define themselves and others, become involved in particular behaviours, conduct their activities, develop relationships and the like (Lorenz Dietz et al., 1994, p. 394). The method lent itself well to the study of visiting as a cultural experience within a Francophone context. It allowed me to uncover culturally relevant meanings and provided “a way of describing, and analyzing the ways in which human beings categorize the meaning of their world” (Aamodt, 1991, p. 41). It facilitated the understanding of experiences and actions within the context of a specific culture and

environment (Aamodt, 1991). Figure 2 clearly depicts the complex, non-linear ethnographic research process, which was followed in this study of visiting experiences.

Figure 2. Ethnographic Research Design (Mackenzie, 1994, p. 777).



### Sample Selection

The purpose of sampling in ethnography is to select participants who have experienced the phenomena under study and who are willing and able to discuss and examine their experience (Mackenzie, 1994). This ongoing process occurred across time and place.

Purposive sampling, a “form of comparative method whereby emerging ideas and possible hypotheses may be tested out in different contexts or with different groups, thus refining constructs and discovering or developing categories,” was used to select participants (Mackenzie, 1994, p. 777). According to Mackenzie:

Random and quota sampling are not appropriate, as the purpose is to identify cues as the study progresses, rather than to identify variables about which deductions have been made, such as the contributions of age or gender to theoretical variation. One of the dangers of quota or stratified sampling is the threat to validity by restricting the informants to specific numbers and restricted categories. (p. 778)

In this study, the goal was to “hear from even more of the participating voices than we currently do” and “to turn directly to lived experience and the related and diverse situations and working local discourses” (Gubrium, 1995, p. 268). Dividing the sample into specific groups would have restricted data collection and would not have allowed for a variety of experiences to be heard. This type of sampling permitted a better examination and understanding of diverse situations.

Recruitment of the sample took place in two long-term care facilities that were primarily Francophone. I contacted the executive director, who managed the two long-term care facilities, by phone to arrange a meeting, which was followed by a letter explaining the study (see Appendix A). The proposal was then submitted to the facilities’ Ethics Committee for review. An approval letter followed and is found in Appendix B. The recruitment process was discussed with the executive director. It was determined that the social worker in each institution would be the best person to give residents and visitors a letter (see Appendix C & D) describing the research and asking them to respond by telephone if they wished to participate.

Nine residents in two long-term care facilities and ten family members who visited the residents took part in this study. Family members were related by blood or marriage to residents who had the capacity to consent as determined by the social workers. Participants were identified as Franco-Manitobans, and as persons who spent time with the residents. Some potential participants chose not to take part in this study.



Most of those refusing did not give any specific reason, however, one person indicated that the timing was not right and her family member's speech impairment would affect the interview. Another resident died before the interview process began.

### Data Collection

In an ethnographic study, the researcher serves as the instrument through which data are generated (Mackenzie, 1994; Rew, Bechtel, & Sapp, 1993). The researcher guides the data collection process by probing for further information in order to achieve depth and clarity. In this study, data collection included initial fieldwork in the long-term care setting, semi-structured interviews with family members and participant observations with family members and residents.

Fieldwork. Prior to conducting interviews and participant observations, I spent time observing in public areas of the two institutions, namely the lobby, cafeteria and auditorium, to become familiar with the culture of the institutions. This fieldwork was essential to set the context as almost none of the empirical investigations to date have considered the setting in which families are involved. Dupuis and Norris (1997) clearly stated that "often, all long-term care facilities are treated as identical structures" (p. 303). In the beginning stages of the fieldwork, the mapping process allowed me to learn the spatial, social and temporal dimensions of the observational setting (Davis, 1986). Spatial referred to learning where specific areas are located, and where certain events occur; social referred to learning about the actors present in the observational setting and why; and temporal referred to information about the ordering of events in the observational setting. Knowing these dimensions of the observational setting helped in delineating the relevant parameters of the study (Davis, 1986).

Interviews. Data were generated using a semi-structured, ethnographic interview guide to provide an appropriate balance of structure and flexibility (see Appendix E). Semi-structured interviews are appropriate when trying to elicit the meaning of events and behaviors for participants (Hasselkus, 1988; Marshall & Rossman, 1995). The format, timing and sequence of questions changed as the data collection process advanced. Sufficient flexibility was needed to allow the researcher to ask clarifying questions as themes emerged (Mackenzie, 1994). For instance, a question regarding whether or not visits took place over the telephone was added. Another question regarding the education level of the resident was deleted because it seemed inappropriate. The question regarding the job description was restructured to better elicit responses. The question regarding whether the participants perceived themselves as caregivers or visitors was changed as there is no one word for “caregiving” in the French language. It was therefore necessary to use the word “caregiving” in English to elicit family members’ perceptions.

Interviews of approximately one to two hours in length were arranged with participants at their convenience. The interviews were tape recorded with consent from participants (see Appendix F & G). Their identity remained confidential and was known only to the researcher and advisor. Each participant provided demographic information, and was asked three types of ethnographic questions: descriptive, structural and contrast (Sorrell & Redmond, 1995). Descriptive or “grand tour” questions provided a general view of the informant’s perspective. Structural questions provided more specific information and were frequently asked concurrently with the descriptive questions. They served to tell the interviewer how informants organized their cultural knowledge (Sorrell

& Redmond, 1995). Contrast questions helped in discovering the meanings of words that informants used to describe their culture, by finding similarities and differences in how they saw the words (Sorrell & Redmond, 1995). Prompts such as “How does that make you feel?” “Will you tell me more about that” and “Is there anything more you would like to tell me?” were used to elicit further information from participants (Parsons, 1997).

Prior to the interviews I met with residents who agreed to participate to introduce myself and to explain the study further. This step in the process proved to be time consuming, yet useful. This time spent together was essential for building rapport with the residents. Most residents wanted to determine who I was and where I was from in order to discover if there were any common connections. Such a discussion is typical among Franco-Manitobans as most know each other or know of some kinship. Others chose to talk about their everyday life and their families.

Interviews took place between July 1999 and January 2000. The interviews were held in private areas such as a lounge or multipurpose room. Most interviews were conducted in French. Two interviews were conducted in English, as it was the preferred language of the participants. One interview was conducted jointly with two participants. These two participants indicated that they both came to see their father on a regular basis, both were quite involved in his care, and they thought it would be beneficial for me to interview them together. A field decision was made to interview the two family members together.

Observations. Participant observations were also conducted with family members and residents following the initial interview (see Appendix F & G). Observation is a fundamental, critical method and is to some degree an essential element of all qualitative

inquiry (Davis, 1986; Marshall & Rossman, 1989). It is considered the method *par excellence* for collecting data for qualitative analysis (Marshall & Rossman, 1989; Marshall & Rossman, 1995). This method is useful for uncovering complex interactions in natural social settings. This special form of observation demands “firsthand involvement in the social world” of the visiting experience (Marshall & Rossman, 1989, p.79). In this case, it involved an immersion in the setting, which allowed me to hear, see, and begin to experience reality as the participants did. The observational period varied from half an hour to an hour and a half and allowed me to explore the interactions between the visitor and the resident. Fieldnotes were taken during the observation and expanded and transcribed immediately after.

Observations took place in a variety of settings. Most occurred in the resident’s room, however, some took place in a main lounge, a patio in the summer and even a shopping mall. Most observations took place approximately one to two weeks after the interview. Two were scheduled immediately after the interview as participants were leaving on holidays or lived some distance from the long-term care setting.

Conducting observational research provided a better understanding of the interconnectedness between the environment in which visiting occurred and how it was perceived and experienced by visitors. Some of the complexities of this approach included “the difficulty of managing a relatively unobtrusive role, and the challenge to identify the ‘big picture’ while finely observing huge amounts of fast-moving and complex behavior” (Marshall & Rossman, 1995, p. 80). The observations were overwhelming at times because of the many factors being observed. In order to remain as

unobtrusive as possible I sat in a corner of the room, participated when family members or residents initiated the contact, and took notes discreetly on a small pad of paper.

### Data Analysis

Following the completion of the first interview, a transcriptionist transcribed the taped interview and data analysis began. The analysis was ongoing and inductive. Each transcript was reviewed for accuracy. This allowed me to “come to a better overall understanding of each participant’s experience” (Parsons, 1997, p. 395). Planning for each subsequent interview was based on data from the previous interview. Therefore, the process of reviewing transcripts prior to the next interview was important because of the potential for prompting additional questions in subsequent interviews (Parsons, 1997). Fieldnotes from the observations also prompted additional questions for subsequent interviews and observations.

The transcribed interviews and expanded fieldnotes were analyzed using Wolcott’s (1994) analytic strategy to develop thematic aspects of the visiting experience. This strategy involved three data transformation features: description, analysis, and interpretation of the culture-sharing group.

Describing the culture-sharing group was essential in setting the stage. According to Wolcott (1990):

Description is the foundation upon which qualitative research is built...Here you become the storyteller, inviting the reader to see through your eyes what you have seen...Start by presenting a straightforward description of the setting and events. No footnotes, no intrusive analysis—just the facts, carefully presented and interestingly related at an appropriate level of detail. (p. 28)

Analysis involved a sorting procedure whereby the transcribed data and fieldnotes were coded and these codes were categorized to reduce the data. The codes were then

clustered into categories according to emergent themes and patterns relevant to the visiting experience.

The interpretation of the stories of the culture-sharing group followed the initial readings and preliminary identification of themes in each of the interviews (Parsons, 1997). It involved a comparison of the themes in each interview and observation, an identification of the similarities and differences, and a selection of the overall themes that best described the experiences of visitors (Wolcott, 1994). Parts of the visitors' stories were drawn upon to illustrate the nature of the visits and the understanding, which emerged from the texts and observations. Selected story extracts reflect the parts which were pertinent to the visitors' particular experiences. My interpretation is merged with the themes arising from the stories shared. I chose to write in the first person to avoid the creation of an authoritative, omniscient narrator as suggested by Goodall (2000, p. 128).

#### Rigour in Qualitative Studies

Koch (1994) indicated that rigour in qualitative research might be established by providing an audit of the events, influences and actions of the researcher. The data collected in both the interviews and observations contributed to the overall rigour and trustworthiness of this study. Many researchers are attentive to the value and trustworthiness of interpretive research findings (Bailey, 1997; Sandelowski, 1993). Hence, it was useful to examine the criteria of credibility, transferability, dependability and confirmability as outlined by Guba and Lincoln (1989) to judge the adequacy of qualitative studies.

### Credibility

Guba and Lincoln (1989) claimed that credibility is maintained when a study presents faithful descriptions of the participants' experiences. In addition, readers who have experienced the phenomenon under study must be able to recognize the experience. In this study, credibility was enhanced by several techniques outlined by Guba and Lincoln (1989). First, I engaged in prolonged discussions of approximately one hour with participants to establish rapport and build trust, which consequently facilitated the understanding of the visiting culture. Second, peer debriefing was useful to increase the credibility of the study. I worked closely with my thesis advisor to discuss various issues encountered in the data collection and analysis process. The process of debriefing was also useful to test out preliminary findings with an outsider. It was also used to help me address my positions and values and the role they played in the inquiry. Finally, to ensure the adequacy of a qualitative study, it was also important to identify personal bias and subjectivity. Hence, it was crucial to record reflections in fieldnotes to monitor my developing construction of the visiting experience.

### Transferability

In this study, transferability was established by "providing as complete a database as humanly possible in order to facilitate transferability judgments on the part of others who may wish to apply the study to their own situations (or situations in which they have an interest)" (Guba & Lincoln, 1989, p. 241). Hence, Wolcott's (1990) strategy was used to describe the culture-sharing group to set the stage and provide a straightforward description of the setting and events.

### Dependability

The authenticity of qualitative research is established when qualitative scientists make the research process visible and hence auditable (Bailey, 1997). An audit trail demonstrates the dependability of the study and the stability of the data over time by describing how the interpretations were generated (Wolcott, 1994). Guba and Lincoln (1989) claimed that an outside reviewer must be able to “judge the decisions that were made, and understand what salient factors in the context led the evaluator to the decisions and interpretations made” (p. 242). In this study, the audit trail described the codes, categories and the interpretations that were generated to give credence to the interpretations. The audit trail provides documentation regarding data analysis and consists of raw data, data reduction and analysis products, memos, and instrument development information (see Appendices H, I, J).

### Confirmability

Confirmability consists of “assuring that data, interpretations, and outcomes of inquiries are rooted in contexts and persons apart from the evaluator and are not simply figments of the evaluator’s imagination” (Guba & Lincoln, 1989, p. 242). In essence, “the themes (parts) and the relationship between the themes (whole)” must capture as accurately as possible the way family members experienced visiting (Parsons, 1997, p. 395). Confirmability was established by returning to the field after the interview to conduct participant observations with family members and residents to determine how well the analyses fit with their experiences. This ensured that the interpretations represented as accurately as possible the visiting experience of Franco-Manitoban family members in long-term care.



In light of the above criteria, Sandelowski (1993) maintained that the best test of rigour in qualitative work is to create “evocative, true-to-life, and meaningful portraits, stories, and landscapes of human experience” (p. 1).

### Ethical Considerations

In research, it is essential to “protect the physical, social and psychological welfare of informants and to honour their dignity and privacy” (Lipson, 1991. p. 335). Basic principles to consider when conducting research with participants include: ensuring that research participants have sufficient information to make an informed decision to take part in the study, that they can refuse to answer any question and that they are aware that they can withdraw from the study at any point. All unnecessary risks should be eliminated and the benefits to society or the individual, preferably both, should outweigh the risks. In this study, several approaches were used to ensure that these basic principles were respected.

Following approval from the Faculty of Human Ecology Ethics Review Committee and the facilities’ Ethics Committee, potential participants at both institutions were given a letter by the social worker at that facility (see Appendix C & D) explaining the study and asking them to respond by telephone if they wished to participate. If both the visitor and resident were interested in participating, the social worker contacted me, gave me the participants’ name and number and I contacted the participants to arrange a meeting time. During the first contact, I provided a verbal explanation of the study (see Appendix F) and both the visitor and resident signed the consent form agreeing to participate in the study (see Appendix G). Before beginning the interviews and observations, I solicited a verbal consent from the family member and resident. It should

be noted that informed consent is an ongoing process whereby consent “needs to be renegotiated as unexpected events or consequences occur” (Munhall, 1988, p. 156). The verbal explanation of the study included the title, purpose, and explanation of the research and procedures to be followed. The risks and benefits were outlined and it was made clear that participants had the opportunity to ask questions and were free to withdraw from the study at any time (Munhall, 1988).

To maintain confidentiality, a code was assigned to each participant. These codes were utilized in fieldnotes, transcripts, data analysis and the manuscript. Only the researcher and advisor have access to the list of participants. It is stored in a locked filing cabinet in a different location than the tape-recorded interviews and the typed transcripts. The researcher and the thesis committee have access to the typed transcripts. The list of participants and any other information identifying the participants will be shredded and destroyed following completion of the research project. The transcripts will be stored in a locked filing cabinet for a period of seven years and destroyed thereafter.

Because of the personal nature of this topic, measures were in place to deal with any emotional discomfort experienced by participants. The interview or observation was stopped if it was apparent that participants demonstrated emotional discomfort. They were reminded that their participation was entirely voluntary and that they had the right to withdraw from the study at any time. In the event of any difficulties or anxiety, participants were to be referred to appropriate resources such as a social worker with the participant’s consent. During some interviews, it was necessary to stop the interview and tape recorder to give the participant some time to regain composure. All participants chose to continue the interviews.

### Summary

Purposive sampling was utilized to identify nine residents and ten family members. Field observations, interviews and participant observations were conducted. Data analysis included description, analysis and interpretation of the culture-sharing group. Rigour was established by following the criteria of credibility, transferability, dependability and confirmability. Ethical issues were taken into consideration.

## CHAPTER 4

### The Lifeworld of Visitors

Chapter 4 begins by setting the context of the study and the lifeworld of visitors. This is followed by a definition of the visiting concept and highlights the components needed to understand visiting. Following this, the dynamics of the visiting experience are explored in vignettes representing participants' stories.

#### Setting the Context

Visiting, just like any other social phenomena, is embedded in specific contexts. Understanding visiting requires that we attend to the contexts in which visits take place. This section begins with participant and visiting profiles. This is followed by a discussion regarding the profiles of the institutions. Setting the context is important, as most of the empirical investigations to date have rarely considered the setting in which families were involved. Dupuis and Norris (1997) clearly stated that "often, all long-term care facilities are treated as identical structures" (p. 303).

#### Participant Profiles

Ten visitors and nine residents from two long-term care institutions participated in this study. Visitors were related by blood or marriage to a resident who had the capacity to consent to the research, spent time with the resident, and identified themselves as Franco-Manitoban.

Family members ranged in age from 46 to 68 years, with an average age of 58. Visitors included six daughters, two sons and two female spouses. Two of the visitors were sisters, who opted to participate in this study together. Six visitors were retired, three were employed outside the home, and one was not employed. Most family

members resided approximately fifteen minutes from the institution, however one person traveled more than an hour to visit.

Residents ranged in age from 68 to 90 years, with an average age of 85. More than half of the resident participants were female (5 out of 9). All of the women were widowed, two of the men were married and two were widowed. Time in long-term care varied from 2 months to 54 months with the average being 15.8 months. Most residents had lived in an apartment prior to entering the long-term care facility. However, one had been hospitalized for over a year and another had lived independently in a house prior to institutionalization. Table 1 summarizes the characteristics of the participants who took part in this study.

#### Visiting Profiles

Visits took place both inside and outside of the long-term care setting. Some even took place over several days. For the majority of visitors, visits were not an everyday occurrence. Only spouses visited daily on a regular basis. Most visits lasted less than an hour, and ranged from five minutes to a couple of days. The time of visits varied, some visited regularly in the morning, afternoon or evening. Others visited when they were able. Many visitors spent time with their relative alone, while others came with their spouse, children, grandchildren or friends. Most residents had visitors other than the family members identified in this study. Table 2 summarizes the characteristics of the visits.

Visits took place in physical and built spaces used for living, working, and visiting. I spent time with visitors and residents mostly in the long-term care setting. One observation took place both inside and outside long-term care; it started in the resident's

Table 1. Participant profiles.

	Visitor (n=10)	Resident (n=9)
<b>Age</b>		
40-49 years	1	
50-59 years	4	
60-69 years	5	1
70-79 years		1
80-89 years		5
90 + years		2
<b>Gender</b>		
Female	8	5
Male	2	4
<b>Marital Status</b>		
Married/Partnered	8	2
Divorced/Separated	1	
Widowed	1	7
<b>Employment Status</b>		
Not employed	1	n/a
Employed full-time	3	n/a
Retired	6	n/a
<b>Relationship to resident</b>		
Spouse	2	n/a
Daughter	6	n/a
Son	2	n/a
<b>Travel time to visit</b>		
≤ 15 minutes	7	n/a
20 – 30 minutes	2	n/a
> 60 minutes	1	n/a
<b>Length of time in long-term care</b>		
≤ 5 months	n/a	4
6 months – 11 months	n/a	2
> 1 year	n/a	3
<b>Place of residence prior to long-term care</b>		
Apartment	n/a	7
House	n/a	1
Hospital	n/a	1

Table 2. Visiting profiles.

	Visitor (n=10)
<b>Site of visits</b>	
Mostly in long-term care setting	3
Inside and out	5
Inside and out overnight	2
<b>Frequency of visits</b>	
Twice a week	3
Every second day	2
Five days a week	3
Every day	2
<b>Length of visits</b>	
≤ 1 hour	6
> 1 hour	3
Couple of days	1
<b>Regular time of visits</b>	
Morning	1
Afternoon	2
Evening	3
Varied	4
<b>Presence of others during visits</b>	
Alone	6
Immediate family	4
<b>Other regular visitors</b>	
Yes	9
No	1

room and continued on a shopping expedition. Although this was the only observation outside the long-term care setting, several visitors indicated that they had visits on the “outside” which demonstrates the permeability of the setting. Two of the visitors indicated that they spent time with residents outside the long-term care setting for a couple of days either at a cottage or at the visitor’s home. One resident’s daughter was particularly encouraged that she could still take her mother out to her home: “I know I can bring her home with me if I want, I can come back tomorrow and go shopping” (I5, 537-539).

Visits took place in a variety of spaces: the resident’s room, the lounge, outdoors on the grounds, during mass in the chapel and in the cafeteria. Visitors and residents spent time together in different spaces for a variety of reasons. Some did not visit in the resident’s room because the room was too cluttered or it did not have a table to play specific games for instance. Others preferred to visit in a common area where they were bound to meet other residents or staff. One visitor was not certain why the resident did not want to spend time together in the room. Those who visited in residents’ rooms preferred more privacy, made use of furniture conducive to playing games, or found it more relaxing. One participant indicated that a visit in the chapel during mass was “one more occasion where we can be with him” and she indicated that having the chapel inside the long-term care facility was “nice, we don’t have to go in the cold, and it’s right here” (I9, 1712-1715).

It became evident during the participant observations that some spaces were not as conducive to visiting as others. For instance, some residents’ rooms did not have appropriate seating or the chairs were not placed in ways to encourage dialogue. As I



entered one resident's room, the visitor was at his mother's bedside questioning her about why she was still in bed at 10 o'clock in the morning. The resident had apparently been reading late into the night and was feeling somewhat tired. The visitor accepted this as normal behaviour for his 90-year old mother. My arrival did not seem to bother them at all until the visitor noticed that I had no place to sit. There were books on a chair, which the visitor moved to make more space. The layout was not conducive to visiting because the resident remained in bed and the visitor sat beside her on a chair. He was not facing her and had to turn to talk to her.

Another visitor played a tabletop game with her mother who sat in a wheelchair while she sat on a closed commode. She made a few humorous remarks about it but did not seem bothered by this arrangement. She indicated that this was not their usual space to play their game. They usually played in the lounge at the end of the hall, which had more space. Unfortunately, this space was occupied at the time therefore they made do with what they had in the resident's room.

### Institutional Profiles

A long-term care facility is definitely a "world of its own" involving a gamut of personalities, including those of residents, family members, visitors, staff, and volunteers. In essence, the long-term care facility is a community and can be treated as a microcosm of the culture and the people within the institution (Savishinsky, 1991).

The study was conducted at Centre Taché and Foyer Valade, two Francophone personal care homes, in the city of Winnipeg. Both institutions are owned and operated by the Sisters of Charity of Montréal (Grey Nuns). The mission for both institutions is based on the spirit of Marguerite d'Youville "who served with compassion, love and

faith” and is “to enrich the quality of life of those we serve” (Foyer Valade, p. 4). This mission is lived out by:

Providing individualized care to the elderly and disabled, thus responding to their total needs – body, soul and mind; through an interdisciplinary approach; in an atmosphere of love, concern, and mutual respect where staff are encouraged to nurture and support each other and other persons they come in contact with – residents, family, visitors and volunteers (Foyer Valade, p. 5).

Centre Taché, founded in 1847, is located in the heart of historic St. Boniface, Winnipeg’s French quarter, and is home to 314 people. It functions as a bilingual long-term care facility for elderly, chronically ill, or disabled residents. Centre Taché is often referred to as “l’hospice Taché” in the Franco-Manitoban community as it was first named. As society’s perception of long-term care settings began to change, so did the name.

To begin my observations, I arrived at Centre Taché on a weekday and parked in one of the stalls reserved for “Visitors.” I had not noticed this sign in the past, but thought that it may be relevant in my observations of the setting. Indeed, during an interview, one participant mentioned that the parking policies enhanced the visiting experience to the long-term care facility as access was easy and the resident did not have far to go when visiting outside the facility. Visitor parking is clearly indicated and is available free of charge on the grounds as posted (see Figure 3 – Photograph indicating availability of visitor parking).

As I entered the long-term care facility, I noted it was a busy place “almost like a small city.” Several residents observed me, a “visitor/stranger”, entering their “home.” I smiled and said “allô” to a group of residents in the entrance. Some chose to greet me, others nodded their heads to acknowledge my presence, while others remained immobile.

I felt welcomed in this common area. Staff and volunteers were busily moving about, returning to work or coming down to the cafeteria for their scheduled break. As I moved through the lobby I noticed a bulletin board – the “Family Circle/Carre-four familial” which was reserved for family members and announced pertinent information on new policies and meetings of the family support group.

Foyer Valade, founded in 1976, was formerly known as the Foyer Saint-Boniface and was located at 271 Archibald Street. In 1988, a new building was erected at 450 River Road in St. Vital. It functions as a long-term care facility dedicated to Francophones who are elderly, chronically ill, or disabled. It can accommodate 115 residents. In this study, participants from Foyer Valade resided on the main level which is a unit “intended for the residents who are self-motivated. Its purpose is to permit them to be as independent as they can be in spite of their personal limitations, which are most often physical disabilities” (Foyer Valade, p. 3). During my first observation of Foyer Valade for this project, I noticed the sliding doors that opened automatically as I entered the long-term care facility. The entrance was bright and inviting, however, there was little activity noted. As I moved along the wide hallway towards the nursing station, I stopped to look at the budgies in the bird cages along the large windows. I continued down the hallway to find several residents in the common lounge, reciting evening prayers. I caught sight of a staff member at the end of another hallway hurrying into a resident’s room. The atmosphere was peaceful, yet hurried.

Both of these facilities had specific policies regarding visiting. For the most part, visitors were welcome twenty-four hours a day, any day of the week. However, Centre Taché’s Resident Information Handbook indicated that “limitations may be imposed if

Figure 3. Photograph indicating availability of visitor parking.



We are fully aware of the importance of the ties you maintain with your family, your friends, etc. They are always welcome at the Foyer. Invite them to come and visit you, or to participate in your activities. Your visitors are most welcome 24 hours a day, any day of the week. Sometimes family members feel they want to do something useful while visiting. Here are some suggestions: accompany you on your appointments outside the Foyer (medical appointments); assist at mealtimes; decorate your room for different occasions; organize events; take care of your clothes and put them away as needed when seasons change; make alterations to your clothing; accompany you to different activities; participate in the Residents' Council; and participate in the interdisciplinary care plan" (p. 27).

Long-term care facilities dedicated to involving visitors in daily life are more likely to have family members and others spend time with residents. These policies affected the time visitors spent in these "places" which had rules and regulations and a culture which visitors soon came to understand.

In the fieldwork I conducted, it was evident that visitors spent time in a setting that they viewed as a "place"; as a setting with manageable units around which to organize and deliver services (Leventhal, Brooks-Gunn, & Kamerman, 1997). Visitors viewed these institutions in different ways. Their experiences were often affected by their perception of the long-term care setting. A positive perception of "place" affected the visiting experience in a more positive way, while a negative perception made the experience all the more difficult. Their perceptions affected their "performances" of everyday life in the long-term care setting as depicted later in this chapter. As Goodall (2000) explained "people act on the world, we don't just move along with it" and the symbolic actions that visitors engaged in were representations of their interpretations of the social world (p. 116).

Interestingly, visitors used a specific terminology in this particular social setting. For instance, they were careful to use the term resident instead of patient. The term patient connotes the illness experience whereas the term resident implies a sense of

permanency and normalcy. The following quotes illustrate the visitors' awareness of the nuances of terminology:

*C'est la relation des gardes-malades avec les patients, les résidents — pas les patients c'est des résidents, je trouve ça merveilleux.* It's the relationship between the nurses and the patients, the residents – not the patients they are residents, I find that wonderful (I1, 1124-1125).

*Puis ils ont beaucoup de personnel et beaucoup de – pas des patients – mais des résidents.* And they have lots of staff and lots of – not patients – but residents (I2, 193-195).

*Puis ceux qui sont des patients ou ceux qui sont des résidents.* And those who are patients, or those who are residents (I2, 1173-1174).

The profiles presented have given a global picture of visitors, visits and institutions. They help set the context in which visits took place and facilitate a better understanding of the concept, visiting.

### Defining the Concept

At first glance, visiting seems simple and straightforward, however the act of visiting is more complex than it appears. Achieving a better understanding of the visiting experience requires an examination of some assumptions about normative situations in which visits take place. This provides a way to uncover the similarities and differences between visiting in long-term care and visiting in other settings.

### Visiting in Normative Situations

Under normative circumstances, a visit is a social act involving a dyadic interaction between the primordial categories of visitor and visitee. For a visit to occur, fundamental requirements are needed: the visitor and visitee acknowledge each other, spend time together, and then disengage. These commonalities were evident in the visits family members experienced in long-term care. However, there is much more to visits

than this, especially in long-term care. The dictionary definition of the term visit provides some preliminary clues. The Oxford Dictionary (1990) defines the term visit as to “go or come to see (a person, place, etc.) as an act of friendship or ceremony, on business or for a purpose, or from interest” (p. 1372). The word visit often connotes friendliness, companionship and caring. However, it is evident that this may not always be the case for all visitors. Minimally, visiting is about spending time with someone, somewhere. Literature on family involvement in long-term care focuses mostly on tasks, that is the “caring for” someone. The Oxford Dictionary (1971) defines to “care for” as: “to provide for, look after, take care of” (p. 115). It is evident that there is much more involved in the “work” of visiting. This study therefore set out to go beyond a task-based definition to examine the concept of “caring about” someone. When we turn to the dictionary definition for this term, it provides some clues. “Caring about” is defined as “to have or show regard, interest, or concern as respecting some person, thing, or event” (Oxford University Press, 1971, p. 115). This view requires a further exploration of the dynamics of the visiting experience.

#### Visiting in Long-Term Care

Visiting involves much more if it is seen as a specific universe of discourse which requires an exploration of the shared symbols of communication and conceptions of reality that are particular to visitors who spend time with residents in long-term care. Words, phrases, and ideas that facilitate interaction and give visitors a sense of identity and belonging must be examined. Outsiders or new visitors must learn the language and assumptions of the culture before they can understand the subtleties of communication or feel secure as visitors in the long-term care setting (Theodorson & Theodorson, 1979).

Hence, this perception of the visiting experience necessitates a further exploration of the lifeworld of visitors.

The production of a satisfactory visit in long-term care for both the visitor and visitee is a delicate and precarious affair. It is necessary to better understand what visits involve. This requires an examination of the components and elements which shape the visiting experience in long-term care. In the next sections, I explore the dynamics of the visiting experience to examine a concept that is assumed to be simple and straightforward, yet is often complex and ambiguous.

### Exploring the Dynamics of the Visiting Experience

Vignettes are presented in this section to depict the dynamics of the visiting experience as told through participants' stories and observed in the field. Involvements, activities, relationships, perspectives, and roles are explored in each of the ten stories<sup>2</sup>.

#### Vignette A – “As long as she has something to look forward to it's hope” Jeanne and Marguerite (daughter and mother)

Jeanne appears to be full of life and energetic as she enters the long-term care setting through the sliding doors. At this point in her life, Jeanne is retired and indicates that she has more time to spend with her mother. She has always been involved in her mother's life perhaps even more so prior to Marguerite's move to the long-term care setting. Marguerite, on the other hand, is a quiet, reserved older woman who does not display much affection. Yet, when Jeanne arrives during evening prayers, she does not hesitate to explain that she can always pray later on, when “the visit” is gone.

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<sup>2</sup> The vignettes are presented in the present tense as this is a common practice utilized by researchers such as Gregory and Russell (1999) and Kellett (1999).



Getting involved. As an adult, Jeanne has always been involved in her mother's life. In a sense, not much has changed since Marguerite's move to the long-term care setting. Her move was a relatively positive experience as Marguerite was able to move to the facility of her choice:

*Elle était prête, alors ça n'a pas été une bataille – même on avait hâte. Et puis elle aussi avait hâte, mais on ne voulait pas, puis elle non plus, d'aller nul part ailleurs.* She was ready, so it wasn't a struggle – we were even looking forward to it. And she was looking forward to it too, but we didn't want, and she didn't want to go anywhere else (I1, 468-472).

They spend time together on a regular basis, sometimes for an hour other times just for a few minutes. Their contact involves phone calls and visits almost everyday. Marguerite usually sits in her rocking chair and Jeanne on the lazy-boy chair. These days, Jeanne finds her visits difficult as Marguerite's thoughts are often focused on her physical health. One of Jeanne's strategies to deal with Marguerite's constant conversations regarding her illness is the use of humour. It is an important part of their visits and is a way of diffusing some potentially long, unpleasant and negative conversations: "*comme j'ai dit, il faut rire à chaque fois, il faut trouver quelque chose de drôle.* Like I said, we have to laugh every time, we have to find something funny" (I1, 351-353).

Part of being involved for Jeanne includes discussing her final disengagement with her mother, that is, Marguerite's death. She explains it as follows:

*Je ne dis pas que je n'ai pas peur de la mort, parce que ça ne serait pas vrai mais si le bon Dieu vient la chercher, moi je suis prête et je pense que les autres sont aussi. Il va venir un jour et j'espère qu'il vienne comme un voleur.* I'm not saying that I'm not afraid of death, because that wouldn't be true but if God comes to get her, I'm ready and I think the others are too. He will come one day and I hope that He comes like a thief (I1, 574-580).

Doing activities. Routine activities seem to characterize Jeanne and Marguerite's time together. For instance, Jeanne calls Marguerite almost every morning at the same

time. This was a routine prior to Marguerite's move to the long-term care setting. They also spend time outside the facility when Marguerite receives her monthly cheque:

*Et c'est moi que s'occupe de ça à chaque fin du mois à la Caisse, j'apporte ça à la Caisse et ça, on en fait une sortie. And I take care of that every month at the Caisse (Credit Union), I bring it to the Caisse and that's it, we make an outing out of it (II, 701-704).*

These routines are important as they are part of giving rhythm to Marguerite's life.

Marguerite always wants to know when Jeanne will be coming back. Jeanne is always somewhat shocked when she hears her mother say:

*Puis la première chose qu'elle me disait c'était, quand est-ce que tu viens. And the first thing she told me was, when are you coming (II, 781).*

Their activities also involve spiritual aspects of everyday life. Jeanne indicates that her mother participates actively in spiritual life. The family recognizes this and Jeanne says: "*Alors on lui donne toujours de quoi à prier. So we give her something to pray about*" (II, 872-873). Jeanne and Marguerite often attend mass together in the long-term care setting. It is also important for Jeanne to know that her mother is not alone when the death of a family member, friend or acquaintance occurs. Jeanne's presence can be viewed as a way of keeping her mother connected to the outside world and as a way of comforting Marguerite if the need arises:

*Je fais sure que je passe un peu plus de temps quand qu'il y a une funérailles. Comme samedi, je suis allée à une funérailles d'une cousine de mon père puis je lui ai demandé si elle voulait venir, non – mais je suis venue avant d'aller à la funérailles puis je suis revenue après avec la petite carte. I make sure that I spend a bit more time with her when there's a funeral. Like Saturday, I went to my father's cousin's funeral and I asked her if she wanted to come, no – but I came before going to the funeral and I came back after with the little card (II, 738-752).*

Giving Marguerite something to look forward to, for instance a grandchild's wedding or a great grandchild's arrival, is viewed as a way of giving her a sense of hope and rhythm to life:

*Mais quand qu'elle vient déprimée un peu, j'e dis déprimée - c'est un peu ça, je ne sais pas quel autre mot me servir, as long as she has something to look forward to it's hope. But when she gets a bit depressed, I say depressed – it's somewhat that, I don't know which other word to use, as long as she has something to look forward to it's hope (II, 502-506).*

It is important to note that there are certain activities or tasks, that Jeanne will not undertake. Other family members share responsibility for these tasks and Marguerite respects this. Jeanne does not know why she cannot do certain things for her mother as she explains in the following comment:

*Il y a deux choses que je ne peux pas faire avec elle, mais elle le respecte – ma petite sœur, ça lui fait rien, je ne suis pas capable d'y rincer les dents, puis je ne suis pas capable de jouer avec les orteils. Puis ma petite sœur vient et puis elle lui lave les dents et puis je n'ai jamais été capable – elle le sait. Je ne sais pas pourquoi, je ne sais pas pourquoi. Mais pour la peigner c'est toujours moi qui l'a coiffé. There are two things that I can't do for her, but she respects that – my younger sister, it doesn't bother her, I can't rinse her teeth, and I can't play with her toes. And my younger sister comes and she washes her teeth and I was never able to do that – she knows it. I don't know why, I don't know why. But to comb her hair, it was always me that did her hair (II, 1430-1440).*

Experiencing relationships. Jeanne surrounds herself with a variety of supports which in turn facilitate her everyday life. One relationship in particular is quite important to her. Her relationship with her youngest brother is very important as it represents a source of great support in dealing with some of the challenges they experience in long-term care:

*Mon petit frère...on a toujours été très proche et puis lui je suis capable d'y parler de n'importe quoi et lui la même chose. Ça fait que de cette façon là tu n'es pas seule. Tu as toujours quelqu'un pour t'épauler. My little brother...we have always been close and I can talk to him about anything and he can do the*

same. So this way you're not alone. You always have someone to support you (I1, 654-662).

Jeanne is especially pleased with the availability of a staff person to interact with and help her solve problems:

*Comme l'autre soir je suis venue, j'avais rien que cinq minutes, juste cinq minutes, mais des fois je viens le matin et le soir, ça fait qu'elle a dit, « Mon doux, ça valait pas la peine que tu viennes ». So là une des gardes-malades a dit, « Bien voyons, au moins elle est venue, pas longtemps, mais elle est venue ». « Bien c'est bien vrai », elle a dit ». Like the other night I came, I only had five minutes, just five minutes, but sometimes I come in the morning or at night, so she said, "Well, it wasn't worth it for you to come". So then one of the nurses said, "Well, at least she came, not for long, but she came". "Well that's true" (I1, 546-555).*

Jeanne expresses her appreciation of the staff and the way she has been able to establish a supportive relationship:

*Alors de cette façon là elle nous aide beaucoup how to cope. Mais il y a un beau personnel ici, je suis contente d'avoir choisi ici. So that way she (the nurse) helps us to cope. They have nice staff here, I'm so happy to have chosen this place (I1, 85-87).*

Acquiring perspectives. For Jeanne, her mother's institutionalization represents a relatively positive experience: "*mais on est tout fier qu'elle est ici... ça été vraiment un soulagement. We are proud that she is here...it really was a relief*" (I1, 139-141). Not only does Jeanne express a sense of relief but also pride. Jeanne further explains: "*moi, je me dis toujours, j'aimerais dont ça finir mes jours ici. I always tell myself, I'd love to finish my days here*" (I1, 197-200). Despite this positive perspective, her comments seem to depict a certain rationalization to diminish feelings of guilt. Jeanne convinces herself that "*elle est mieux ici quand même. She's better off here anyway*" (I1, 525-526). A sense of guilt may be present, but Jeanne must accept the decision and she rationalizes the situation:

*Des fois je suis frustrée mais d'autre fois, la plupart du temps c'est correcte. Si ça fait pas mon affaire ou son affaire, et c'est réciproque hein, alors moi j'ai juste à m'en aller. Sometimes I'm frustrated but other times, most of the time, it's all right. If it's not going my way or her way, it's reciprocal, heh, so all I have to do is leave (I1, 535-539).*

Adopting roles. Jeanne sees her role as being there for her mother on a regular basis. She defines it in social terms and also in some task-based activities. Yet the main gestalt of her visits is to spend time with her mother:

*Je viens de plus en plus souvent parce que, elle a quand même une maladie et puis ça lui fait mal – mais je me dis, je peux le faire, puis quand même que je donnerais quelques années de ma vie, j'en ai d'autres. I come more and more often because she does have an illness and it is painful – but I tell myself, I can do it, and even if I gave a few years of my life, I still have more (I1, 1187-1195).*

Jeanne considers her time spent with her mother as time that she has to give and is glad to do so. Although she is engaged in various activities, her visits mostly involve the social aspect of visiting, that is, spending time with someone.

Vignette B – “We can observe things...” – Marc and Claire (son and mother)

Marc and his mother, Claire, often visit in Claire's clean and cozy room which has been her home for the past five months. Her room is filled with treasured articles including pictures of her children, and grandchildren, knick-knacks of all sorts and some religious artifacts. The books laying on one of the chairs are evidence of one of Claire's hobbies; reading. There is a walker, one large recliner and a small metal side chair in the small room which is her “chez-nous”<sup>3</sup>. Claire, a witty and active woman approaching her tenth decade of life, accepts herself as she is “I won't change and anyway I'm too old to change” (O2). She is somewhat embarrassed to speak with me because of a speech impediment, yet we were able to communicate effectively. Marc is aware of his mother's

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<sup>3</sup> The term “chez-nous” in the French language means home.

embarrassment and explains that he takes a role in encouraging Claire to continue participating in social life. Her calm disposition and her continued love of life make visits a pleasant experience. Marc and his spouse spend time with Claire on a weekly basis. He is a retired person who has set clear goals to achieve while visiting his mother. At once serious, he tells his story with a humorous twist.

Getting involved. *“Ce n'est pas moi qui l'a trainé ou la tiré par la patte pour l'amener ici,”* exprime Marc, d'un ton sérieux, *“elle a décidé elle-même que c'était pour le mieux pour elle. Et pour nous c'était mieux parce qu'on s'inquiétait tout le temps”*. “I did not drag her to bring her here,” Marc says, in a serious tone of voice, “she decided on her own what was best for her. And for us it was best because we worried all the time” (I2, 65-70). For Marc and his spouse visits are different now compared to those in the community. *“Mieux qu'avant, beaucoup mieux qu'avant. Ah oui,”* explique Marc. “Better than before, much better than before. Definitely,” explains Marc when comparing his present experience to their experiences in the community (I2, 914-915). It is more positive because the worries and the multitude of tasks he and his spouse had to perform have diminished: *“Ah, c'était un rythme de support qui est beaucoup plus différent qu'ici. Ah, it was a rhythm of support that was much different than the one we have here.”* (I2, 844-845). Claire's relocation to the long-term care setting represents a sense of relief and reassurance for Marc and his spouse:

*Franchement, pour nous, c'est aussi bien que pour elle, parce qu'il n'a pas d'inquiétudes, il n'a pas d'inquiétudes de minute à minute, jour à jour comme on avait.* Honestly, for us, as well as for her, because there are no worries, there are no worries from minute to minute, day to day like we had (I2, 283-287).

Marc's interaction with his mother appears to be positive. They seem to enjoy each other's company and are affectionate towards one another, as I observed. He sums up their interaction this way :

*Comme des fois elle peut être un peu déprimée ou malheureuse avec quelque chose puis des fois c'est du – c'est ma mère et je me trouve responsable. Qu'est-ce que je vais faire c'est de la taquiner, puis si ça marche pas, je vais être plus rigide dans ma présentation.* Like sometimes she may be a bit depressed or unhappy with something and sometimes its – she's my mother and I find that I'm responsible. What I'll do is tease her a bit, and if that doesn't work, I will be more rigid in my presentation (I2, 676-683).

Doing activities. Although Marc engages in social activities with his mother such as attending events organized by activity workers or sharing a meal, he is more preoccupied with his mother's overall quality of care and quality of life. He engages in activities to monitor Claire's well-being in the long-term care setting. He is not shy in questioning his mother about her daily life and often focuses conversations on his mother's needs:

*Bien, ce n'est pas une litanie de questions, mais je lui pose des questions, comment ça va – je me rappelle la dernière visite, des affaires comme ça. Qu'est-ce qui est arrivé à... et en plus de ça je veux m'assurer qu'elle sait c'est quoi son calendrier d'activités, je passe au travers de ça.* Well, it's not a litany of questions, but I ask her questions, how are you doing – I remember the last visit, things like that. What happened to...and on top of that I want to ensure that she knows what's on her calendar of activities, I go through that (I2, 657-664).

One of the ways Marc evaluates Claire's quality of life is by monitoring his mother's attitude during their visits:

*Des fois son attitude – je suis toujours inquiète de son attitude envers les affaires. Donc je guette ça, si elle devient un peu, être bête et agaçant un peu trop, elle n'est pas trop heureuse avec un des affaires ou malheureuse avec ci puis ça, ou qu'elle ne veut pas.* Sometimes her attitude – I am always worried about her attitude towards things. So I watch for that, if she has become a bit, hard-headed or bothered a bit much, if she isn't happy with something or miserable with this or that, or that she doesn't want to (I2, 598-604).

Spirituality is another way for Marc to connect with his mother. Giving Claire a reason to pray is an approach Marc uses to provide rhythm to his mother's life and provide her with continuity:

*Elle va à la messe presque à tous les jours, elle va au chapelet l'après-midi, puis elle prie pour moi puis je lui ai donné des petites choses pour dire à propos de moi.* She goes to mass almost everyday, and she goes to say her rosary in the afternoon, and she prays for me and I give her little things to say about me (I2, 896-900).

Marc contributes to his mother's adaptation to the long-term care setting by equipping her with the skills to cope with the relocation and to receive the care that she needs. He enables her rather than doing for her by speaking to staff with her, not by himself. It is part of empowering her and maintaining her independence:

*Parce que des fois elle veut que quelqu'un fasse quelque chose ici, j'y touche pas, je le fais pas, je ne veux pas aller leur dire, je vais avec elle leur dire.* Because sometimes she wants someone to do something here, I don't touch it, I don't do it, I don't want to go tell them, I go with her to tell them (I2, 211-215).

Marc views his participation as a way of knowing what tasks need to be done or actually performing a specific task. He clearly states that he does not see visiting as a task in itself:

*Je ne dis pas que je vois ça comme une tâche, je voyais ça comme visiter sa mère. C'est compris que c'est différent que – c'est mieux qu'où on était. Là c'était des tâches qu'on avait.* I'm not saying that I see it as a task, I saw it as visiting my mother. It's understood that's it different than – it's better than where we were. Then we had tasks (I2, 1317-1322).

He further explains that it is not necessary to have a list of planned tasks to do when visiting in long-term care as compared to the community setting:

*Alors ici, ce n'est pas dire qu'on va venir ici pour faire ceci ou pour faire ça.* So here, it's not like we say we're coming to do this or to do that (I2, 139-141).



Experiencing relationships. Marc experiences several contacts in the long-term care setting. His presence in this setting becomes meaningful as a consequence of his interactions with others. To ensure that his mother's needs are met, Marc has regular contact with staff. However, there seems to be some reluctance on his part to address certain issues with staff for fear of saying the wrong thing or being perceived as "demanding": "*C'était pas demandant mais c'était raisonnable.* It wasn't demanding, it was being reasonable" (I2, 549-550). Marc states that his relationship with staff is a way of meeting his goal of helping his mother with her daily habits:

*Pour nous c'est de s'inquiéter, bon disons que ça n'avance pas, qu'elle ait le service, alors on veut être certain. Ce n'est pas pour être exigeant mais c'est parce qu'elle ne demande pas, et des fois c'est pour la pousser. Il faut que je vous explique quelque chose – c'est de lui aider avec ses habitudes.* For us it's to worry, well let's say that things aren't getting anywhere, that she gets the service, so we want to be sure. It's not being demanding but it's because she doesn't ask, and sometimes we have to push her. I have to explain something – it's to help her with her habits (I2, 86-93).

Marc's visiting experience includes cîner residents :

*Qu'est-ce qu'on fait la plupart du temps, si la porte de ses voisins est ouverte, moi et ma femme on va aller dire allô...bien on ne sait pas combien de visiteurs ils ont...de savoir que quelqu'un connaît leur nom ça fait quelque chose. Ça prends rien leur dire allô.* What we do most of the time, if her neighbour's door is open, my wife and I will say allô...well we don't know how many visitors they have...just to know that someone else knows their name it does something. It doesn't take much to say allô (I2, 1086-1101).

One of Marc's most important sources of social support is his spouse. She is the one he turns to when trying to understand the visiting experience and his relationship with his mother:

*La seule chose qui était difficile, la chose que j'ai trouvé difficile, c'est de discuter qu'est-ce qui arriverait si quelque chose sérieux arriverait à sa santé – qu'est-ce qu'on va faire avec ça? La fois qu'on a songé à l'affaire un peu, puis heureusement que j'ai une bonne épouse pour discuter.* The only thing that was difficult, the thing that I found difficult, was to discuss what would happen if

something serious happened to her health – what would we do with that? The time that we thought about it a bit – thankfully I had my good spouse to discuss things with (I2, 1034-1042).

Other family members who spend time with Claire include her grandchildren and great grandchildren. Marc is proud that they have an opportunity to know their grandmother. It is not easy to be the nearest sibling; Marc resents the situation somewhat and is annoyed with his mother's perception of their involvement:

*Il fait beaucoup pour elle...comme elle ne voit pas de la manière de qu'est-ce qu'on fait nous autres, tu sais, qu'on vient ici tous les jours. Ce n'est pas qu'on veut être récompensé pour ça mais...He does a lot for her...like she doesn't see it the same way that is what we do, you know, when we come every day. It's not that we want to be rewarded for it but... (I2, 1183-1189).*

Acquiring perspectives. Marc is frank about how he views his mother's institutionalization; he tells it like it is. His initial involvement in long-term care was on a daily basis, however, the frequency of visits diminished for the following reasons: "*On veut qu'elle soit indépendante et aussi on veut avoir une vie.* We want her to be independent and also we want to have a life of our own" (I2, 53-54). This change occurred as a result of his ongoing involvement in the long-term care setting. Over time he recognized that his presence on a daily basis may not be beneficial to Claire nor to himself and his spouse. He rationalizes the situation this way:

*Il y a toujours quelqu'un qui vient alentour, et même si elle vivait avec nous autres, on ne peut lui donner le service puis l'interaction entre le monde qu'elle a ici.* There is always someone who comes around, and even if she lived with us, we can't give her the service and the interaction that she has with people here (I2, 892-896).

He sums up a visit by expressing that soothing his soul is important and that is exactly what a visit does for him. He explains it as follows:

*Une visite – c'est le confort de sa mentalité si tu veux. De lui aider à être confortable. C'est peut-être une tâche, de lui aider à être confortable.* A visit –

it's the comfort of the mind if you want. To help her to be comfortable. It may be a task to help her to be comfortable (I2, 1330-1333).

Finally, Marc indicates that his presence is about being there for his mother:

*Elle veut nous avoir alentour, elle veut nous voir, on fait certain qu'on lui donne le temps privé, bien, c'est ça qu'elle aime.* She wants to have us around, she wants to see us, we make sure that we give her private time, that's what she likes (I2, 82-85).

Adopting roles. According to Marc, he is in the best position to monitor Claire's adaptation to her new environment. He and his spouse plan visits at specific times to observe how Claire is adapting to her "chez-nous":

*On essaye d'arriver souvent à peu près une demi-heure ou trois-quarts d'heure avant l'heure du dîner, c'est-à-dire à midi, et voir qu'elle s'intéresse à manger parce que des fois – puis ils ont beaucoup de personnel et beaucoup de – pas des patients – mais de résidents, alors malgré qu'ils donnent le service, la chose est c'est que nous autres on peut observer les choses qui sont un peu différent. Il ne faut pas oublier que ça prend du temps pour qu'elle s'ajuste.* We try to come about half an hour or three quarters of an hour before lunch, that is at noon, and see that she's interested in eating because sometimes – and they have a lot of staff and a lot of – not patients – but residents, so although they give the service, the thing is that we can observe things that are a bit different. We can't forget that it takes time for her to adjust (I2, 188-200).

Marc focuses on monitoring Claire's quality of life and quality of care and her adaptation to her new environment. Visiting helps Marc meet his goal, which is:

*“S'assurer de son confort. Je pense que c'est la chose plus simple.* To ensure her comfort. I think it is the simplest thing” (I2, 1195-1197).

Vignette C – “I owe it to my mother” - Paul and Évelyne (son and mother)

Paul and Évelyne are very affectionate towards one another. Évelyne hangs on to her son as much as she can. She really misses him. Paul describes their greetings in the following way:

*Toujours un baisé, une caresse, des mots - je t'aime, je te manque. On est une famille pas mal affectueux sur son côté...alors, non on n'a pas peur d'y donner un*

*gros bec et un gros baisé, et lui dire bon je t'aime.* Always a kiss, a hug, words – I love you, I miss you. We are an affectionate family on that side...so, no we're not scared to give a big kiss and tell her I love you (I3, 673-680).

Paul is employed full-time and has a family of his own. He makes time to visit Évelyne who is in her mid seventies. Évelyne is a proud woman who surrounds herself with things she likes: a portrait of her family, photo albums, a rosary. She has just recently moved to her new home and continues to adjust to make this a "chez-nous."

Getting involved. Paul explains that his family has always been close and that visiting has always been an important part of maintaining a relationship with his parents throughout his adult years:

*Bien disons, qu'on visitait toujours nos parents quand qu'ils demeuraient dans leur propre appartement, comme couple. Alors visiter ça toujours été important dans notre famille.* Well, we always visited our parents when they lived in their own apartment as a couple. So visiting has always been important in our family (I3, 10-14).

For Paul, his involvement in long-term care has been a difficult journey. He has not quite accepted the fact that his mother needs this level of care. He finds it difficult to accept that he and his spouse are unable to provide this care at home. At one point he states that his mother's move to long-term care was a mistake:

*Je pense que c'est une erreur, parce que je la visite, puis je vois que son moral est toujours bas. Et pas rien que ça, je veux dire, elle a tellement changé, je ne sais pas si c'est à cause du stroke ou si les médicaments l'on changé...puis le problème est, c'est que ce n'est plus la même femme, ce n'est plus la femme que je connaissais.* I think it was a mistake, because I visit her, and I see that her morale is always low. And not only that, I mean, she has changed so much, I don't know if it's because of the stroke or if the medication has changed...and the problem is that she's not the same woman, she's not the same woman I knew (I3, 76-85).

Yet, Paul has taken the first step towards accepting this move. Recognizing that the long-term care setting is the best environment for Évelyne at this point in her life helps him to view the long-term care facility as a place to call home:

*Comme c'est là, je pense qu'elle est probablement où est-ce qu'elle devrait être et nous autres, notre rôle comme enfants, c'est de s'assurer qu'elle n'est pas oubliée et de venir la voir assez souvent et lui dire qu'on l'aime.* Right now, I think that she's probably where she should be and for us, our role as children is to ensure that she is not forgotten and to come and see her often and tell her that we love her (I3, 529-535).

Despite recognizing the benefits of this move, Paul continues to feel ambivalent about the placement and questions whether it was the right decision. His distress is evident in the following comments:

*Et puis quand lui est décédé, c'était une surprise pour nous autres, ça bouleversé la vie de la famille. Et puis on en souffre encore aujourd'hui. Des décisions ont dû se faire vite et puis moi je trouve qu'on a pris des décisions trop vite et on a appris à vivre avec ça.* And when he (father) died, it was a surprise for us, it turned the family's life upside down. And she still suffers today. Some decisions had to be made fast and for me, I find that we made the decisions too fast and now we have learned to live with that (I3, 43-49).

Despite Paul's ambivalence, the disengagement experience is made easier because he does not have to worry about Évelyne's safety and well-being when he leaves:

*Et puis, c'est plus facile ici, c'est bien plus contrôlable. Je ne suis pas obligé - une fois que je pars d'ici j'ai pas besoin de m'inquiéter* And, it's much easier here, it's much more controllable. I'm not obligated to – once I leave I don't have to worry (I3, 495-499).

Doing activities. Paul and Évelyne enjoy a variety of activities together. Paul is quite content to engage in specific activities with his mother:

*Elle sort plus aujourd'hui qu'elle a jamais sorti. Mais pour nous autres ça nous donne une activité à faire avec elle.* She goes out more often now than she ever did. But for us, it gives us an activity to do with her (I3, 571-574).

Paul spends part of his visits monitoring Évelyne's mental health. One of his strategies is to spend time together to compensate for the loneliness Évelyne experiences in long-term care:

*Aussi son humeur, quand je viens, ça débouche – je m'ennuie. Alors je passe une heure avec, deux heures avec, je suis venu passer deux heures avec elle samedi et*

*on a eu du fun ensemble.* Her humour, when I come she let's go – I'm lonely. So I spend an hour with her, two hours, I came and spent two hours with her on Saturday and we had fun together (I3, 142-147).

Often, Paul is faced with difficult conversations because of Évelyne's level of mental functioning. It is a loss which he explains as follows:

*Je pense que son - her attention span - je pense que ça ce n'est pas comme ce l'était avant, 15 minutes, 20 minutes - la mémoire, elle pense à quelque chose d'autre ou elle est perdue. Quand qu'elle se fatigue elle est perdue aussi.* I think that her attention span, I think that it's not like before, 15 minutes, 20 minutes – the memory, she thinks of something else or she is lost. When she's tired she's lost too (I3, 164-169).

Another component of his visits is to provide some continuity in his mother's life.

For instance, Paul ensures that his mother receives the weekly Francophone newspaper,

*La Liberté:*

*Elle lit encore sa Liberté - tout ça on s'assure qu'elle a ces contacts là.* She still reads her *Liberté* – we ensure that she has these contacts (I3, 1044).

Reminiscing is also an important part of visits. Retaining a connection with the past is important to Paul and is a way to facilitate interesting conversations:

*Souvent on va parler de qu'est-ce qui s'est passé dans la vie, des petits secrets de famille, des histoires, des mariages.* Often, we will talk about what went on in life, family secrets, stories, marriages (I3, 1066-1070).

Though the memories are foggy, Paul and Évelyne love to talk about the past and sometimes even about the present. But they rarely talk about the future.

*On lui dit qu'il est mort et elle part à pleurer. Elle dit, comment ça se fait que je ne le sais pas, pourquoi je n'ai pas été aux funérailles, des affaires comme ça. Ça c'est tough, et puis je pense que si on l'avait amené à la maison du début, je pense que ça aurait probablement été différent. Elle n'aurait pas descendu dans des dépressions si vite, ou peut-être que non.* We tell her that he (husband) is dead and she starts crying. She says, how come I don't know that, why didn't I go to the funeral, things like that. That's tough, and I think that if we would have brought her home from the beginning, I think it would have probably been different. She wouldn't have gone into depressions so fast, or maybe not (I3, 92-101).

Experiencing relationships. The visiting experience for Paul involves contacts with others. Acknowledging other residents is part of Paul's personal mission in the long-term care setting. He really sees this as a good deed which does not take much:

*Si tu viens visiter juste une personne puis tu n'es pas capable de donner ton temps à quelqu'un d'autre, bien tu manques un appel. Moi, quand je viens, j'essaye d'amener un peu de joie à ceux que je vais rencontrer, même si c'est juste une minute ou deux ou trois secondes, juste leur donner la main, quelque chose, des affaires de même. If you come to visit just one person and you're not capable of giving your time to someone else, then you're missing a calling. When I come I try to bring a bit of joy to those that I meet, even if it's just a minute or two, or three seconds, just to give them a handshake, something, things like that (I3, 377-286).*

Interaction with staff ranges from just acknowledging their presence to speaking with them when an issue arises. It is evident that regular contact with staff is limited in Paul's case. Paul indicates that he stays out of their way and does not bother them unless absolutely necessary as evident in these comments:

*De temps en temps, c'est rare. On sait notre chemin ici, on leur dit allô. Le seul temps que je vais leur parler c'est si - comme l'autre jour elle a perdu sa montre ou son collier, ça fait que là tu vas leur parler, et tu leur dis, as-tu trouvé ça...ça fait que tu cherches pour deux heures, tu le trouves pas et tu vas voir le personnel - et souvent tu vas le trouver dans une autre chambre. Well sometimes, it's rare. We know our way around here, we say allô. The only time that I will talk to them – like the other day she had lost her watch or her necklace, so you go to talk to them, and you say, did you find this...so you don't have to search for two hours, you can't find it and you go see the staff – and often they will find it in another room (I3, 983-998).*

Others outside the long-term care setting, especially family members, are a source of social support for Paul as described by the following:

*Je vais parler avec mes frères, je leur dis, bon bien la mère a dit ça, c'est tu vrai - parce que des fois elle va me dire des affaires, je ne sais pas si c'est vrai ou non, alors je vérifie avec mes frères et ma sœur. I'll talk to my brothers, I tell them, well Mom said this, is it true because sometimes she tells me things, I don't know if they're true or not so I check with my brothers and my sisters (I3, 608-613).*

Acquiring perspectives. An African proverb describes the notion of continuity quite well: “when an older person dies; a library burns”. This proverb applies to Paul’s experience and to the importance that he attributes to Évelyne’s knowledge:

*Et moi j’ai dit, écoutes, c’est ta job de te rappeler de ça, moi je me souviens jamais des noms, je sais même pas son premier nom. Elle le savait, mais là elle s’en rappelait pas - puis elle le réalise, mais il faut l’encourager et lui dire, écoutes - un, tu vieillis, deux, un stroke affecte la mémoire et trois, il faut que tu recommences en neuf. Les tiroirs sont là, il s’agit de les trouver, chaque jour. Mais elle est pas pire.* And I said, listen, it’s your job to remember that, I never remember names, I don’t even remember first names. She knew, but she didn’t remember – and she realizes it, but we have to encourage her and say, listen – one you’re getting older, two, a stroke affects the memory and three you have to start over. The drawers are there, you have to find them everyday. But she isn’t too bad (I3, 649-659).

Making the time to visit allows for the feelings of guilt to diminish. Paul explains how his feelings of selfishness, his guilt and his feelings of duty affect his visiting experience. He would rather have made a different decision to eliminate these negative feelings:

*Bien ça me fait réaliser qu’un jour, on est vieux puis ça me fait réfléchir et puis à penser un peu que je suis un peu égoïste. Vraiment ma mère devrait être chez nous, parce que je dois ça à ma mère. Elle a pris soin de moi quand j’étais jeune et puis pourquoi que je ne l’ai pas fait, je ne sais pas, ça ne veut pas dire que ça changerait pas.* Well, it makes me realize that one day we get old and it makes me reflect and think a bit that I’m a bit selfish. Really, my mother should be with us, because I owe it to her. She took care of me when I was young and why I didn’t do it, I don’t know, it doesn’t mean that it won’t change (I3, 418-426).

Even though Paul’s involvement has been difficult from the beginning he has acquired a positive perspective regarding his mother’s presence in his life:

*Okay, qu’est-ce qui est agréable, c’est quand que je vois qu’elle est en bonne forme. Je veux dire, elle paraît bien, elle a 75 ans, elle paraît très bien. Et quand que je vois qu’elle tient à son sens d’humeur, elle a un très bon sens d’humeur, quand qu’elle a son sens d’humeur – disons que c’est très rare qu’elle ne l’a pas, du moins ce qui est plaisant pour moi c’est quand je la vois, 90% du temps elle est assez heureuse.* Okay, what’s pleasant, it’s when I see that she is in good shape. I mean she looks good, she is 75, she looks really good. And when I see that she



holds on to her sense of humour, she has a really good sense of humour, when she has her sense of humour – let's say it's very rare that she doesn't have it, so what's pleasant for me is when I see, 90% of the time she is relatively happy (I3, 924-934).

Adopting roles. Paul focuses on monitoring his mother's quality of life and quality of care. Yet, he continues to experience difficulties accepting his mother's life situation. He expresses feelings of guilt through his story as well as a sense of duty towards his mother. Paul is able to go beyond these sentiments and find some satisfaction in spending time with his mother:

*Et puis quand qu'elle n'est pas heureuse, ça prend pas de temps à la ramener - et ça c'est satisfaisant. Parce que je sais que ça ne prend pas de temps - et qu'il y a des façons de - elle aime bien la prière. And when she is not happy, it takes time to bring her back - and that's satisfying. Because I know that it doesn't take too much time and there are ways to - she likes prayers (I3, 934-946).*

Vignette D – “I can spend time with her” – Joanne and Roseanna (daughter and mother)

Joanne is a reserved woman who spends time with her mother on a regular basis. She is retired and finds that she has time to spend with her mother. Roseanne is a woman in her nineties who likes to keep busy. Her room demonstrates her need to continue collecting items and keeping her home clean. She cares for her many plants and likes to talk about the success she's had with them since her move to long-term care. This daughter and mother pair are not very demonstrative regarding their affection for each other. Little emotion is shown between Joanne and Roseanna as they greet each other. Roseanna is happy to see Joanne and has a million things to tell her about her day. Joanne visits her mother on a weekly basis: *“Je viens à peu près deux ou trois fois par semaine quand je suis capable de venir. I come about two or three times a week when I can”* (I4, 13-14). They also speak on the phone everyday to keep in touch:

*Puis des fois elle oublie qu'elle m'a téléphoné, so elle me retéléphone encore. Elle dit, je t'ai pas appelé encore – mais je voulais savoir comment ça va aujourd'hui.* And sometimes she forgets that she's called me, so she'll call back again. She says, I haven't called you – but I just wanted to know how you were doing today (I4, 358-362).

Getting involved. Joanne and her siblings are relieved that Roseanna is now in long-term care. They made the decision together after admitting that they were too worried when Roseanna lived in the community. In this setting, Joanne believes that her mother is in good care:

*C'était notre première priorité, c'est qu'on ne voulait pas trouver ma mère tombée à terre dans une suite avec pas de soins pendant deux, trois, quatre ou peut-être même huit heures, parce qu'elle tombe facilement.* It was our first priority, we didn't want to find my mother fallen on the ground in her suite without care for two, three, four or even eight hours, because she falls easily (I4, 124-129).

It is evident in Joanne's comments that a burden has been lifted since Roseanna's move to the long-term care setting:

*Puis depuis qu'elle est ici, on sait qu'il y a vingt-quatre heures de surveillance. Ça nous a enlevé un énorme fardeau. Parce que là, s'il y a quelque chose au moins on sait qu'elle a de l'aide, même si elle est très indépendante.* Since she's been here, we know that there is twenty-four hours surveillance. It has removed a large burden. Because now, if there is something at least we know that she has help, even though she is very independent (I4, 170-176).

Doing activities. Joanne engages in specific activities with her mother when she visits Roseanna in long-term care. They discuss everyday life, for instance, what is going on in the world or in the family. Joanne shares what she has been doing in her garden, for instance and she gives Roseanna the opportunity to discuss things that are relevant for her, for example feeding the rabbits that roam outside on the grounds of the long-term care setting. They rarely talk about the past as Joanne explains:

*Pas vraiment, je ne veux pas commencer ça, parce que je veux qu'elle vit dans le présent...Elle a une bonne mémoire pour ça. Mais pour quelque chose de*

*présent, elle oublie facilement.* Not really, I don't want to start that because I want her to live in the present... She has a good memory for that. As for the present, she forgets easily (I4, 736-745).

Joanne and Roseanna engage in some religious activities with which provide another activity for them to share:

*C'est quand t'est-ce qu'ils ont eu l'extrême-onction des malades, bien j'ai été avec elle. Je lui ai dit, moi aussi je veux voir ça, j'ai été avec elle. Elle était bien contente. Ah oui, j'ai participé avec elle à des activités – quand je viens puis il y a quelque chose, je vais avec elle. Puis si elle dit qu'elle est fatiguée, elle veut monter, bien là on monte.* When they had the sacrament of the sick, well I went with her. I told her I want to see that so I went with her. She was happy. Oh yes, I've participated in activities with her – when I come and there is something going on, I go with her. And when she says she's tired, she wants to go up, well we go up (I4, 542-552).

Other activities include going out to the mall. However, this type of outing involves some unique challenges as described by Joanne:

*Mais à part d'activités qu'on fait des fois on prend la chaise roulante puis on va se promener. Ou des fois, moi j'ai une auto, je peux arriver – elle se lève toute seule, elle s'assoit dans mon auto puis après ça moi je prends la chaise roulante puis je la plie et la mets dans mon hatchback. Puis l'auto est juste la bonne hauteur pour elle, parce qu'il faut qu'on la relève avec des coussins parce qu'autrement elle serait trop basse. Puis des fois on va au St. Vital Shopping Centre avec elle et on marche le mall. Puis on fait ça – l'hiver dernier on a fait ça deux ou trois fois. Ça la fatigue par exemple. Mais au moins ça lui fait une sortie.* But other than that, sometimes we take her wheelchair and we roam around. Or sometimes, I have a car, so I come – she gets up by herself, and sits in my car and after that I take her wheelchair and fold it and put it in my hatchback. And the car is just the right height for her, because I have to get her to sit higher with cushions otherwise she's too low. And sometimes we go to the St. Vital Shopping Centre with her and we walk the mall. And we did that two or three times last winter. It's tiring for her though. But at least it's an outing for her (I4, 438-454).

Joanne is responsible for her mother's finances and also explains that she engages in cleaning Roseanna's room because she has a tendency to keep everything. Joanne also runs some errand as requested by her mother:

*Ah, des petites affaires – acheter des kleenex, des bas de nylon, des livres Search the Word – ce n'est pas des grandes affaires, toujours des petites affaires. Peut-être acheter une livre de noix, des bonbons, des choses comme ça. Puis à Noël, qu'est-ce qu'on fait, c'est qu'elle retire de l'argent puis elle achète trois ou quatre grosses boîtes de chocolat pour traiter le staff. C'est des commissions comme ça qu'elle nous demande. Ah little things – buy kleenex, nylons, books like Search the Word – it's not big things, always small things. Maybe buy a pound of nuts, some candy, things like that. And at Christmas, what we do, she takes money out and buys three or four large boxes of chocolate to treat the staff. It's those kinds of errands that she asks us to do (I4, 473-484).*

In the long-term care setting, Joanne and Roseanna like to share a snack together in the dining room. However, their favourite past-times is playing dominoes:

*Le seul temps qu'on la fatigue c'est quand qu'on joue au dominos, parce que là ça prend beaucoup de concentration, parce que le domino c'est quelque chose qui lui tient la mémoire très vite parce qu'il faut qu'elle compte, il faut qu'elle fasse ses points. The only time we tire her out is when we play dominos, because it takes a lot of concentration, because dominos is something that keeps her mind very active because she has to count, she has to make points (I4, 629-635).*

Joanne finds that this is a way to keep her mother connected. She takes the opportunity to compliment her mother as she explains:

*Oh, elle est connectée. Je dis tout le temps, maman vous êtes connectée vous, le cerveau est connecté – pour faire des jeux de même... Parce qu'elle n'oublie pas facilement son jeu, elle aime bien ça. Oh, she is connected. I always say, mom you're connected, the brain is connected – to play games like that... Because she doesn't forget her game easily, she really likes it (I4, 642-656).*

Experiencing relationships. As for others in the long-term care, Joanne finds that they do not bother her during her visits with Roseanna. Joanne usually acknowledges their presence. She explains their involvement as follows:

*Je ne trouve pas ça difficile de venir, non. Je trouve que c'est accueillant aussi, c'est vraiment bien. Et puis quand qu'on vient, c'est toujours privé. Comme t'as vu ils nous laissent tranquille. Si je viens ici jouer avec maman, ils nous laissent tranquille. C'est pareil comme à la maison. It's her home, et elle est contente d'y revenir. I don't find it difficult to come, no. I find that it's inviting too, it's really nice. And when we come it's always private. Like you saw they leave us alone. If I come here to play with mom, they leave us alone. It's just like at home, and she's always happy to come back (I4, 1154-1162).*

Joanne does not seem to know the staff very well, yet she and her mother take the time to speak with them. Joanne describes this relationship in the following quote:

*Des fois il y a des femmes, je ne sais pas si c'est des gardes-malade ou bien des aides qui nettoient ou des choses comme ça, puis on parle avec eux. Sometimes there are women, I don't know if they're nurses or aides who clean or something like that, but we chat with them (I4, 1431-1434).*

Joanne and her siblings have established some visiting routines. They usually visit their mother individually and try not to come all at once. They have also started a log book to know who has been to visit as Joanne explains:

*J'ai été visité maman aujourd'hui, comme ça t'as pas besoin d'y aller toi aujourd'hui, tu iras demain. On essaye de ne pas venir tout ensemble. De toute façon elle s'en rappelle pas. So on a mis un livre dans l'entrée puis à chaque fois que quelqu'un vient visiter on marque la date, on marque qui vient. I went to visit mom today, so you don't have to go today, you can go tomorrow. We try not to come together. Anyway, she doesn't remember. So we put a book in the entrance and each time someone comes to visit we mark the date, we mark who comes (I4, 291-298).*

Acquiring perspectives. Spending time in the long-term care setting has allowed Joanne to develop a worldview of this setting and how her mother is adjusting to it:

*Même si elle dit qu'elle s'ennuie des fois, mais quand qu'elle dit qu'elle s'ennuie c'est parce qu'elle est fatiguée, c'est le temps qu'elle vienne se reposer. Mais elle n'a pas vraiment le temps de s'ennuyer ici, parce qu'il y a toujours quelque chose. Even if she says she is lonely sometimes, but when she says she's lonely it's because she's tired, it's time that she takes a rest. But she really doesn't have to be lonely here, because there's always something (I4, 528-534).*

Joanne accepts that she must play a role in encouraging her mother during difficult times. For instance, Roseanna is not quite sure that the long-term care setting is the best place for her. Joanne explains the situation as follows:

*Les premiers temps elle avait toujours envi de pleurer parce qu'elle se sentait comme -- je suis venue ici pour mourir. J'ai dit, maman mourir ici ou mourir dans la communauté, tomber à terre et avoir souffert avec une hanche cassée, qu'est-ce que vous préférez? Mourir là-bas ou mourir ici en paix avec tout le*

*monde et puis avoir des soins. Elle a dit, c'est vrai, quand j'y pense comme ça c'est vrai, j'ai rien à me plaindre.* At first, she was always on the verge of crying because she felt like – I came here to die. I said, mom, dying here or dying in the community, falling and suffering from a broken hip, what do you prefer? Dying there or dying here in peace with everyone and with all the care. She said, that's true, when I think about it like that it's true, I have nothing to complain about (I4, 528-534).

Adopting roles. Joanne is aware that Roseanna is worried about the burden she is putting on her daughter, yet Joanne is able to explain it to her mother as follows:

*Ça l'agasse un peu parce que je vois que des fois elle se met à pleurer parce qu'elle dit – tu vois comment je te donne du trouble. Bien je dis, maman, vous pensez pas que je vous en ai donné du trouble dans ma jeunesse?* It bothers her a bit because sometimes I see that she starts to cry because she says – you see how much trouble I'm giving you. Well I say, mom, don't you think that I gave you some trouble during my youth? (I4, 820-825).

Joanne explains that her visits are not always easy :

*Des fois c'est dure, mais comme je te dis, le Seigneur m'accorde bien de la patience parce que des fois il faut que je répète cinq fois.* Sometimes it's difficult, but like I said, God gives me the patience because sometimes I have to repeat things five times (I4, 805-808).

Joanne indicates that she has a role to play in increasing her mother's overall well-being by encouraging her to think positively. She continues to feel responsible for her mother's personal growth even at ninety years of age:

*Mais j'essayais toujours de la remettre sur le point de pas penser aux critiques, penser positif. Parce qu'elle pensait souvent, souvent négatif, on ne grandit pas quand qu'on est comme ça, pensez positif maman, pensez toujours les plus belles choses des personnes, puis ça va vous améliorer votre feeling en dedans.* I always tried to bring her back and not to think so critically, but to think positive. Because she often had negative thoughts – we don't grow when we think like that, think positive mom, always think of people's qualities, and it will enhance your feelings inside (I4, 1016-1023).

Joanne considers her time spent with her mother as a duty. She is responsible for ensuring her mother's happiness and takes this role seriously:

*Ça serait le temps qu'on passe avec ma mère c'est un temps précieux parce qu'on ne sait pas comment longtemps encore qu'elle sera avec nous, et on va prendre l'occasion de cette journée là de vivre pour qu'elle soit heureuse pour la journée. Pour moi, c'est une job pour moi de voir que ça va se dérouler bien pour elle dans la journée. Pour moi c'est un devoir, de voir que ma mère est contente... Pour moi, c'est un devoir qu'il faut que je fasse pour ma mère. It would be the time I spend with mom, it is a precious time because we don't know how long she will be with us, and we will take the opportunity to make this day to live so that she is happy for the day. For me, it's a job to see that her day goes well. For me it is a duty to oversee my mother's happiness...For me it is a duty to do this for my mother (I4, 1577-1614).*

Vignette E – “You realize how very fortunate you are” – Jocelyne and Madeleine

(daughter and mother)

Jocelyne is a quiet and reserved middle-aged woman who spends time with her mother, Madeleine, at least once or twice a week. Madeleine is a vibrant, active senior who enjoys her visits. She lives in a room full of memorabilia and other things that are meaningful to her. Their visits often occur outside the long-term care setting because of Madeleine's high level of physical functioning.

Getting involved. The purpose of most of their visits is to spend time together. When issues arise that may threaten the social nature of their visits, Jocelyne is uncomfortable. Recently, staff requested that Jocelyne and her sibling speak to their mother about her hygiene:

When they told my sister that my mother had BO, so she phones me, and she says, you've got to help me out here, how are we going to – you know, we never did approach her about it. I don't know how you handle that, when you have somebody who's still got their faculties. What are you supposed to do...I said to my sister, why are they telling us that, that's up to them to look after them, that's what she's here for (I5, 712-718).

Jocelyne is reluctant to raise the issue with her mother because it may negatively impact the pleasant social nature of their visits. She explains that this task-related activity should be the responsibility of staff.

Doing activities. Jocelyne and Madeleine spend time visiting grandchildren, going out for supper or on shopping trips to the mall. Jocelyne's time with Madeleine consists of being able to offer her mother the small joys in life. Jocelyne explains that Madeleine enjoys spending time in Jocelyne's home:

I don't think we realize what it's like for them in here. Like she's just in awe of smelling when we're preparing food, like she says we never get that here and that usually helps her appetite. So things like that (I5, 12-17).

For Jocelyne, visiting her mother is like visiting anyone else; "it's not like we have to try and make conversation, it's just there" (I5, 463-464). Conversations between Jocelyne and Madeleine are often about everyday life, not unlike conversations that any visitor might have with another person. These chats help to ensure continuity and a connection to the outside world. According to Jocelyne:

As far as visiting here, it's usually, like I'll sit in her room and we'll talk, and she wants to discuss everything, things she's read in the papers because she gets the newspaper every day and we'll discuss that. And maybe things that kind of bother her about here (I5, 79-86).

Experiencing relationships. Other actors in Jocelyne's visiting life include her family and occasionally staff. Her siblings provide a way for Madeleine to keep in touch with her mother if she is not able to visit for a week:

Yeah and when I think us kids get together, like if I'm visiting with my sister and my brother, or whatever, yeah you say, well I stopped in to see Mom, and this, this and this, we kind of keep ourselves in the know I guess. If I haven't been able to come in one week and I know my sister has, we'll discuss some thing (I5, 546-555).

Her sisters especially have been involved in activities to help Madeleine with the organization of her room:

My mother has a lot more stuff in her room than the rest of them do. Probably because she's more active and does more crafts and whatever, but I could see where her room was getting really kind of cluttered, and so we decided we'd come



down and do a real cleaning and haul stuff away. Well I tell you, there was four of us, four sisters in there all day, and it didn't really look a whole lot different when we left. She won't part with anything, she needs that for her crafts, and we respect her. I feel that it's more important to me for her to have the things she wants, and I mean if we take anything way from her...heh I don't care if it's piled up to the ceiling (I5, 561-583).

As demonstrated earlier, her relationship with staff does not reflect a partnership or collaboration. A clear division of tasks exists between Jocelyne and the staff. She explains that they do not have much contact except for greeting each other in the hallway. She further explains that the care her mother receives is not discussed with her:

That's (the care) never discussed with us – yeah that's funny, and yet we get a phone call about that. No, other than the signing when we take her out, that kind of stuff, and saying – or sometimes, when I come they're in there giving her a needle or whatever (I5, 1073-1080).

Acquiring perspectives. Jocelyne explains her enjoyment of the visits comes from being able to spend as much time as possible with her mother before she dies. Visiting her mother is a way for Jocelyne to express her affection towards Madeleine. Feelings of guilt also emerge regarding the amount of time Jocelyne's spends with her mother:

It really makes you realize how very fortunate you are to still have her around. You know, the day is going to come when we're not going to be able to come and see her. So I enjoy every time that I get to spend with her, knowing that the day is going to come where I'm going to wish that I probably should have done more of it. She has a really good sense of humour, so we can really enjoy her personality (I5, 914-925).

Even though these feelings of guilt are usually present, Jocelyne acknowledges that visiting her mother provides her with peace of mind. Knowing that her mother is happy and enjoys her "home" is important to Jocelyne. Their conversations allow Jocelyne to monitor these sentiments which in turn reassure her:

And just quality time, just being able to talk to her and finding out what her week was like and all the things that happened. Then I feel more that I know that she's relatively happy, here, she's not, you know, I think that's important to me. I wouldn't want her – I wouldn't be able to handle it coming to see her and finding out that this happened and that happened and I hate it here – and I would just take her out. But I never get any of that. She seems to be happy here. She loves leaving though for a few days, and it comes to, well I have to go back, you know (I5, 1297-1312).

Spending time with Madeleine gives Jocelyne an opportunity to give back a little bit of what her mother gave her: "She's always been there for any of us you know; emotionally, financially, it didn't matter what, she's always, always there – and she's still like that" (I5, 418-421). Visits make it possible for Jocelyne to be close to her mother. Recently, Madeleine told Jocelyne some childhood secrets which have helped Jocelyne to better understand her mother. Jocelyne feels that she has become even closer to Madeleine since then and explains:

I'm glad that I can spend time with her because I understand where she came from and why, and feel that I need to make up for maybe some of the closeness we didn't have then, you know (I5, 405-409).

Although Jocelyne acknowledges that little has changed since her mother's move to long-term care, she cannot help but express feelings of guilt:

Like the only thing that's changed, as far as I'm concerned, is this little room she's got, and I feel bad about that. There's lots of times I think you know, she really should be with one of us, where she could have a nice big room for her stuff and more, you know (I5, 831-837).

Jocelyne compares her present experience with her mother with that of her father who resided in long-term care but had dementia. Visiting was very different for her and was almost seen as a task in itself as she explained in the following quotes:

It's just like it always was, you know, you just carry on from – like she's not at a point where – I know with my Dad, when we use to go and visit him, it's not like, how do you keep the conversation going, and what are we going to discuss, because there wasn't and he couldn't remember a whole lot of – although, way

back, he would remember way, way back, we'd discuss stuff from way back, or do you remember the time when this happened – you would keep trying to keep his memory active (I5, 442-453).

Adopting roles. Madeleine's independence affects how Jocelyne interacts with her during their visits. Taking on a task-based role is not an option for Jocelyne at this stage:

A big difference. And I think a complete different type of visit all together with my Mom and somebody who is like that (has dementia). Because you're more concerned with – mind you, there are times, like when I've had her at home, I'd like to maybe rub her feet and I don't feel comfortable even asking her. I don't know how she would react to my asking (I5, 501-509).

Jocelyne takes on a traditional visitor's role where her energies are concentrated on social aspects rather than on tasks.

Vignette F – “You get used to it...”– Dolorès and Adélar (wife and husband)

Dolorès visits her husband, Adélar, on a daily basis. Their visits are very routine and systematic and Dolorès knows exactly what she will be doing when she enters the doors of the long-term care setting. Adélar was an active man prior to his illness which has left him with limited mobility and a speech impairment. He continues to have a sparkle in his eye when he sees her. Dolorès is a dedicated spouse who really believes in the words “till death do us part.” She herself is aging, yet finds time and more importantly energy to spend with her husband. Adélar lives in a spotless and simply decorated room. He has all the important items, that is, the TV, pictures of grandchildren and of his working years, and awards. Dolorès has decorated for the fall season with a Thanksgiving wreath to show her husband that she thinks of him.

Getting involved. Since her husband's move to the long-term care setting several years ago, Dolorès continues to find it difficult to accept that Adélar can no longer live

with her in the family home. Her involvement in the long-term care setting has not been easy to define. Dolorès explains to me that she has tried to change her routine, but it was too difficult for her:

*Alors j'ai essayé de ne pas venir et puis, j'étais comme inquiète, j'aime mieux venir voir... Bien ça m'inquiète parce que je me demande qu'est-ce qu'il pense lui quand je ne suis pas ici – qu'est-ce qu'elle fait, tu sais. So I tried not to come and I was worried, I'd rather come and see... Well I was worried because I wonder what he's thinking when I'm not here – what is she doing, you know (I6, 123-131).*

Dolorès defines her presence in terms of ensuring that her husband's needs are met and that the care she and the staff provide is of good quality:

*Je me sens très bien là, je suis contente, parce que je sais qu'il a bien dîné, bien mangé, et puis il est de bonne humeur. I feel really good, I'm happy because I know that he's had a good lunch, he's eaten well and he's in a good mood (I6, 160-162).*

Knowing that her husband is in a good mood makes her involvement all the more pleasant. Yet there are times when she must find satisfaction in others as she explains:

*Bien je suis toujours fière d'arriver puis voir comment qu'il est. S'il a un sourire sur le visage bien ça, ça change la journée un peu, d'autres journées il ne l'est pas. Il y a des journées où il est très de mauvaise humeur. Dans ce temps-là je parle aux autres. Je fais semblant que je m'aperçois pas. Well, I'm always proud to arrive and see how he is. If he has a smile on his face well it, it changes the day a bit, on other days he isn't. There are days when he is in a really bad mood. When that happens, I talk to others. I pretend that I don't notice it (I6, 44-51).*

Doing activities. Dolorès' visits are focused on ensuring specific and routine tasks are completed. Their daily routine rarely varies. She arrives exactly at 9:00 a.m. every morning and describes the routine as follows:

*Dans le patio là, et puis on prend un café et on remonte vers onze heures et demi, et puis là j'attends son dîner, et puis c'est moi, bien des fois il ne peut pas manger seul... alors c'est moi qui coupe sa viande et qui le fait manger. Ensuite, je le prépare, je change sa bib et je lui verse de l'eau, et je mets son T.V. – son control et la lumière près de lui, et je pars. Alors c'est mes visites à tous les jours ça. In the patio there, and we have a coffee and we go back up around eleven thirty and*

then I wait for his lunch, and I, well often times he can't eat on his own so I'm the one who cuts his meat and helps him eat. Then, I get him ready, I change his bib and pour him a glass of water, and put his TV on – his control and his light near him, and I leave. So that's my visits every day (I6, 13-23).

After their morning coffee they return to Adélarde's room just in time for medication and lunch. This part of the visit is spent watching television, talking, waiting for medication, and then waiting again for lunch. Dolorès waits patiently for the nurse to prepare her husband's medication so that she can give it to him. She exits the room and meets the nurse in the nursing station. During this time, her husband tells me that his physical condition is "*c'est plus difficile pour elle que pour moi*; more difficult for her to accept than for him." Dolorès brings the pills back in a small cup and gently puts them into Adélarde's mouth. She gives him some water to wash down the pills. Dolorès helps her husband with lunch because he needs assistance with his meal. They watch a television show together and she departs only when she has ensured that her husband is comfortable; has the TV on his favourite channel, and has access to all the things he needs for the rest of the afternoon such as a glass of water with a straw, and the emergency pull cord to call the nursing staff. She knows that he will have an afternoon nap once she leaves.

Experiencing relationships. Dolorès and Adélarde enjoy each other's company during this time, if Adélarde is in a good mood. Their conversations are limited as described by Dolorès:

*Non, non jamais. Il ne parle pas du – parce que c'était un homme qui était toujours sur le golf course, le golfing puis le bowling. Puis jamais, jamais qu'il le mentionne, puis j'en parle pas parce que, peut-être qu'il n'est plus capable de faire ces choses là puis c'est peut-être mieux de ne pas lui en parler, parce qu'il ne le mentionne pas.* No, no never. He doesn't talk about – because he was a man who was always on the golf course, golfing and bowling. And never, never, that he'll mention that, and I don't talk about it either, maybe because he can't do

those things anymore and maybe it's better not to talk about it, because he doesn't mention it (I6, 511-519).

Dolorès does not initiate conversations about the activities Adélarde used to enjoy. They discuss everyday life such as what they want to watch on television or what will be on the lunch menu. The memories are all too vivid for them. Dolorès and Adélarde rarely talk about the past but they do discuss the present. During difficult moments, Dolorès appreciates the presence of others in the long-term care setting:

*Les autres résidents, qui sont dehors et puis leurs visiteurs. Parce que, quand qu'il est de mauvaise humeur il ne parle pas du tout. Puis je reste parce que je n'ais pas pour partir parce qu'il parle pas, je suis accoutumée à notre régime qu'on a à tous les jours alors.* The other residents who are outside and the visitors. Because when he is not in a good mood he doesn't talk at all. I stay because I'm not going to leave because he's not talking. I'm used to our routine that we have every day (I6, 87-93).

Often, simple contacts with others in the institution make visits more pleasant for Dolorès and Adélarde. These contacts leave Dolorès feeling good about her time spent visiting in the long-term care setting. The following remarks illustrate these sentiments:

*Oui. Et il en a plusieurs ici aussi, qui n'ont pas de famille, je pense, alors quand je passe un peu de temps avec eux autres, puis je pense qu'ils deviennent – quand je rentre au x<sup>e</sup>, comme toutes ces personnes là – comme on dirait that I'm part of their family. Je sais pas, peut-être qu'eux autres deviennent attachés à nous, de nous voir à tous les jours.* Yes, there are many here also that don't have any family, I think that when I spend a bit of time with them and I think that they become – when I enter the # floor, all those people – it's like I have become part of their family. I don't know maybe they become attached to us because they see us every day (I6, 913-922).

Dolorès' relationship with staff represents a positive yet delicate association.

There is reluctance on her part to address certain issues with staff for fear of saying the wrong thing or being perceived as a troublemaker:

*Il faut bien raisonner et puis prendre un pas arrière avant de – parce que, les employés ici sont très, très bons, très bons. Alors, je fais bien attention.* We have

to think and take a step back before going – because the employees here are very good, very good. So I am very careful (I6, 424-428).

She does appreciate the rapport that she has built with the staff. She also feels reassured in knowing that Adélarde also knows the staff well:

*Alors, il y a des choses, maintenant, à cet'heure, s'il me dit quelque chose, il faut que je raisonne avec la garde-malade un peu au lieu de discuter ça avec lui... Ah oui, oui, bien pas seule, mais on est tous ensemble puis la garde-malade va entrer dans la chambre puis on jase de toute sorte de choses. So there are things, sometimes, now, if he tells me something, I need to think it through with the nurse instead of discussing it with him... Yes, yes, not alone, we're all together and the nurse will come in the room and we talk about all kinds of things (I6, 396-408).*

Acquiring perspectives. When asked about her experience, Dolorès can only express the following words: “you get used to it.” She further explains that this is her life now and reluctantly accepts the situation:

*Non, non, non. C'est ma vie maintenant, puis... Ça fait, encore c'est quelque chose qui a changé dans ma vie puis c'est devenue une routine. La même chose à tous les jours. No, no, no. That's my life now, and...It's like, again it's something that has changed in my life and it's become routine. The same thing everyday (I6, 841-845).*

For Dolorès, her husband's relocation represents a very difficult situation to accept. There seem to be feelings of guilt and sadness associated with the institutionalization of her husband:

*Ah bien, c'était une question très difficile, parce que j'aimerais mieux l'avoir à la maison. Ça te fait un peu mal au cœur de les laisser ici, mais il vient un temps que – là, il ne peut plus sortir de sa chaise lui-même, puis il est obligé de rester ici, on n'a pas de choix. Oh well, that was a very difficult question, because I would rather have him at home. It breaks your heart to leave them here, but there comes a time when – he can't get out of his chair on his own, and he has to stay here, we don't have a choice (I6, 28-34).*

Adopting roles. Time spent together allows Dolorès to express her affection towards her husband; it provides an opportunity for physical contact; it gives the feeling of being needed; it provides an opportunity for conversation; and it occupies time.

For Dolorès, it is satisfying to see that her husband is in a good mood. This provides her with a sense of reassurance and relief that things do go on in her absence :

*Alors quand je le vois de bonne humeur, quand je viens puis qu'il est de bonne humeur je file très bien parce que je sais que tout s'arrange Bien. So when I see him in a good mood, when I come and he is in a good mood, I feel very good because I know that things are going well (I6, 74-78).*

Vignette G – “Well he’s our father...” – Diane, Simone and Lucien (daughters and father)

Diane and Simone, two middle aged sisters, continue to be close in their adult years. During the interview, this closeness was evident as one would finish the other’s sentence. They wanted to do the interview together because both are involved in their father’s life. Diane and Simone both spend time with their father, Lucien, almost everyday. Their visits are often tense and when issues cannot be dealt with, they think the best thing to do is leave. Their father is always very happy to see them. However, he can be quite difficult at times. Lucien worked hard all his life and lived through some difficult times. Now, he lives in a simple room decorated with a few family pictures and some religious images and symbols. Diane accepts their situation and states:

*Bien c’est notre père. Puis, je veux dire, il a été bon pour nous autres, c’est un bon père...alors on est tu pour l’abandonner à ce point-là? Well he’s our father. And I mean, he was good to us, he’s a good father...so are we going to abandon him at this point? (I7A, 282-284).*

Getting involved. Simone feels that spending time with her father is a source of comfort. Her visits have the following purpose:

*Bien c’est qu’on l’a vu et on sait qu’il est correct. Je pense que c’est un confort pour nous autres de savoir qu’il est bien. Well, it’s that we saw him and we know he’s all right. I think that it’s comforting for us to know that he’s all right (I7B, 1801-1804).*

Only a few words are said about the future:



*So, quand qu'il a abouti ici, pour nous autres c'était un soulagement. Puis pour lui aussi, puis il était – quand qu'il a entré ici, ah bien la dernière fois que je vais partir – la prochaine fois, il dit, que je vais déménager je ne le saurai pas. Bien c'est la réalité, ça il l'a accepté.* So when he ended up here, for us it was a relief. And for him as well – when he moved here, ah well the next time I leave – the next time, he says that I move out I won't know it. Well that's reality, and he's accepted it (I7B, 846-853).

Doing activities. Diane and Simone find their visits difficult because their father has “no more interests now.” Simone explains that her father watches the news somewhat but that's all. His world has become “very, very small” (I7, 25). Diane believes that as her father's eye sight and hearing diminished he lost interest in the television.

Conversations are always a challenge – it's a good day when Diane or Simone can get their father to talk about the past and not dwell on a specific subject, especially if he's distraught because of the day's events. The subject matter can dictate whether they spend a good half-hour or an exhausting one. Simone characterizes these visits in the following way:

*Ça fait que ce n'est plus plaisant nos visites. Comme on les gardent courtes. Moi, je viens souvent et elle aussi, je viens régulièrement, comme à peu près cinq fois par semaine, mais des fois, après quinze ou vingt minutes quand j'en peux plus, je dis bye-bye papa, je reviendrai demain ou après demain.* So our visits are not pleasant anymore. Like we keep them short. I come to visit often, and I come regularly, like about five days a week, but sometimes after fifteen or twenty minutes, when I can't take it anymore, I say bye-bye papa, I will come back tomorrow or after tomorrow (I7B, 99-107).

Diane and Simone take a role in monitoring their father's well-being:

*Et comme, même pour lui, d'exprimer qu'il était déprimé, c'est nous autres qui le voyait dans nos visites.* And, even for him to express that he's depressed, it's us that see it during our visits (I7A, 2133-2135).

Simone has often been the one to intervene in difficult situations whether it be between her father and the staff or her father and other residents. This makes their

relationship somewhat tense at times and Simone is quite certain that this may have affected their relationship in a negative way:

*C'est pour ça qu'il se choque plus contre moi, parce qu'il y a quelques fois que c'est moi qui a intervenu.* That's why I think that he gets more angry at me, because there are a few times that I intervened (I7B, 142-144).

Diane has quite a specific routine when she visits her father. It is often at the same time and limits are set to make leaving easier. For instance, Diane visits for approximately forty-five minutes before supper. Her strategy gives her father some rhythm to life and it avoids his begging her to stay longer. Planning the exit makes it easier for her to leave:

*Il soupe à cinq heures moins quart, so j'arrive vers quatre heures, on a notre petite visite, et vers cinq heures moins vingt c'est le temps de souper, alors là on marche à la cafétéria ensemble puis je m'en vais. Même si c'est juste trois quart d'heure, c'est assez... Puis il y a une raison de quitter, parce qu'autrement, bien tu pars déjà, bien reste donc un autre cinq minutes.* He has supper at a quarter to five, so when I arrive at four, we have our little visit, and around twenty-to-five it's time for supper, so then we walk to the cafeteria together and I leave. Even if it's just three-quarters of an hour, it's enough... And there's a reason to leave, otherwise, well you're leaving, well stay for another five minutes (I7A, 314-325).

As for specific tasks, Diane takes care of her father's finances and they both do errands as needed. Other tasks are left up to staff for the following reasons:

*On veut qu'il profite – comme un autre exemple, c'est de lui couper les ongles. Moi, je refuse à chaque fois. On veut qu'il utilise les services – le monde sont là pour t'aider à faire ces choses là. Plus, si on fait ces petits soins là, et il y a un problème, eux autres ne seront pas conscients qu'il y a un problème. Tandis que si c'est eux qui font tous les soins, eux autres se rendent conscients s'il a un rash, s'il a ceci ou ça, s'il a besoin de quelque chose, ils nous contactent. Mais si on fait ces chose là, vraiment il n'a plus besoin qu'on fasse des choses physiques pour lui.* We want him to benefit – like another example is to cut his nails. I refuse every time. We want him to use the services – the staff are here to help you with those things. Plus, if we do those small care tasks and there is a problem, they won't be conscious that there is a problem. But if they provide all the care, then they become conscious that he has a rash, or this or that, if he needs something, they contact us. But if we do those things, really he doesn't need us to do those physical things for him (I7, 963-975).

Experiencing relationships. Diane and Simone are strong believers in keeping their father involved in family life. The word family to them means the extended family, including their father, themselves, their partners, their children and their grandchildren. Diane explains it this way: “*on est une famille complète qui est avec toi pour avoir du fun.* We are a complete family here with you to have fun together” (I7A, 216-218). Their father often does not see it that way. It is often a struggle to get him to participate in social activities:

*“Alors j’ai dit qu’est-ce que ça donne de rester assis dans ta chambre à ruiner des affaires quand tu peux faire des choses plaisantes. Mais je sais pas....Je sais qu’il y a des enfants qui on arrêté de visiter pour des raisons comme ça. So I said, what good is it for you to stay in your room to mull things over when you can be doing pleasant things. But I don’t know...I do know that some children have stopped visiting for those kinds of reasons”* (I7B, 245-274).

Family gatherings continue to be important for both Diane and Simone, yet they express the following in regards to Lucien’s participation in these activities:

*Des fois ces choses là sont beaucoup plus importantes pour nous autres que pour lui. Comme on voudrait qu’il fasse ces choses là. Puis c’est vrai, pour nous autres c’est important qu’il soit là pour ces occasions là. Pour lui ça devient important une fois qu’il est là...Il est un peu aussi dans le self pity, tu vois, puis si on peut l’amener à faire des choses hors de son self pity, tu sais. Sometimes those things are much more important to us than to him. Like we would want him to do those things. And it’s true, for us it’s important that he be there for those occasions. For him, it becomes important once he’s there...He is a bit in the self pity, you see, and if you can get him to get out of the self pity* (I7B, 755-773).

They both say that they come quite often and that they see it as necessary because of Lucien’s lack of social contacts within the institution: “*parce qu’il n’a pas grand contact avec d’autres personnes ici.* Because he doesn’t have much contact with other people here” (I7B, 376-377).

To their surprise, Diane and Simone discovered during the interview that their routines are not quite the same. Diane prefers to visit her father in his room immediately after work while Simone enjoys having coffee with him in the lounge. Diane explains her preference as follows: *“moi ça me repose. Comme je me reposerais pas, il me semble, en avant où il y a des résidents qui passent.* It relaxes me. Like I wouldn't be able to relax, it seems, in the front with all the other residents going by (I7A, 1234-1238).

Simone can only come after supper and she explains her preference for meeting other people, having a cup of coffee and being able to relax. A sense of community is also depicted in the following quote:

*Tu vois, moi, quand je viens, je l'amène en avant, puis là des fois il y a d'autres qui viennent et on jase un peu, puis là lui s'intègre à cette conversation... On lui donne tout le temps son café – nous autres, je viens toujours au café... Bien je ne sais pas si c'est important pour lui, mais c'est important pour moi. Bien, tu sais, après une journée de travail, moi j'ai besoin de m'asseoir puis me détendre, puis j'aime ça dans l'entrée, et le monde entre et sort, puis ça nous donne quelque chose à jaser, puis on prend notre café. Bien tu viens que tu développes avec les autres membres des familles. Bien il y en a beaucoup – c'est francophone, on connaît beaucoup de gens ici, en général, puis tu leurs parle – un petit mot ici et là, puis c'est le fun. You see, when I come I bring him to the front and then sometimes other people come and we chat and he joins in the conversation... We always give him a coffee – I always come for coffee... Well I don't know if it's important for him, but it's important for me. Well, you know, after a days work, I need to sit down and relax, and I like it in the entrance, and the people come and go, and it gives us something to talk about, and we have our coffee. Well you begin to develop with other families. Well there are many – it's francophone, we know a lot of people here, in general, you talk to them – a word here and there and it's fun (I7B, 1098-1142).*

Both Diane and Simone have contact with staff when necessary. Simone is the one who deals with issues most often as her job permits her to call staff during the day. They play the role of advocate and ally with the staff as explained in the following quote:

*Ils nous tiennent exactement au courant de ce qu'il se passe. Comme à un moment donné je le trouvais déprimé, puis j'en ai parlé à la garde-malade puis ils l'ont mis sur des anti-depressant pour un bout de temps. Mais on a vu un*

*changement aussi, par exemple, il était moins négatif...Lui ne parlerait plus pour lui-même, de ces choses là. They keep us up to date on things that are going on. Like at one point I found him very depressed, and I talked about it with the nurse and they put him on anti-depressants for a while. But we saw a change, for example, he was less negative...He wouldn't talk for himself about these things anymore (I7A, 2110-2115).*

Acquiring perspectives. Diane and Simone support each other in the care of their father. Diane explains the difference between a social visit and an involved visit this way:

*C'est pas juste des visites parce qu'il y a le côté social...des fois c'est juste une visite quand qu'il y des étrangers, c'est différent, c'est plus une visite. It's not just visits because there's the social side...sometimes it's just a visit when there are strangers, that's different, it's more a visit (I7B, 2519-2522).*

After her visits which are often filled with challenges, Diane accepts the fact that the visits are this way and that she must find satisfaction in spending time with her father. Perceiving her experience in this sense provides her with the opportunity to sooth her soul. Diane comes to the conclusion that:

*On ne peut pas le faire faire des choses qu'il ne veut pas, alors la chose qu'on peut faire pour lui c'est de le visiter, finalement, c'est là la satisfaction c'est qu'on est venu le visiter puis on est correct. We can't make him do things that he doesn't want to do, so the thing that we can do is visit, finally, that's the satisfaction, it's that we came to visit him and we are all right (I7A, 1848-1854).*

Diane also finds that in some instances, she is amazed at her father's sharpness, wittiness and wisdom:

*C'est drôle, des fois il sort avec des choses et des fois ils ne sont pas plaisantes, mais souvent il sort avec des petites – il va dire des choses qui te ramène les deux pieds ça terre...Il sort avec choses que tu te dis – you know, il en connaît plus que nous autres encore...Il a quand même une sagesse. It's funny, sometimes he comes up with things and sometimes they aren't pleasant, but often he comes up with little – he'll say things that bring your two feet back on the ground...He comes up with things and you tell yourself – you know, he still knows more than us...He does have a certain wisdom (I7A, 1888-1932).*

To continue some traditions and to give Lucien rhythm to life, Diane and Simone describe the following:

*On lui achète des biscuits et des boîtes de kleenex...puis des chips – puis vraiment ce n'est pas nous autres. Parce que, quand qu'on vient il aime ça nous offrir de quoi à manger – alors c'est pour nous autres. Puis lui bien, on a de quoi à manger alors il est content. We buy him cookies and boxes of kleenex...and chips – and really it's not for us. Because when we come he likes to offer us something to eat – so it is for us. And for him, we have something to eat so he's happy (I7A, 1065-1076).*

*Mais il ne serait pas choqué qu'on le sort du chapelet, il est content d'avoir de la visite. But he would never be mad that we took him out of the rosary, he's happy to have visit (I7A, 1175-1177).*

Simone knows what it takes to be able to spend time with her father in long-term care. She is able to clearly articulate what she is experiencing:

*Il faut avoir la parlette, il ne faut pas être gêné, il faut être capable de prendre beaucoup de choses avec un grain de sel ou avec de l'humour. Il faut être capable de sonder le terrain puis si c'est un bonne journée, dans quelle direction t'en aller, puis si ce n'est pas une bonne journée, t'essayes de choisir une autre direction. Il faut savoir aussi quand partir...Il faut vraiment être à l'écoute de qu'est-ce qu'il se passe, puis quand ça va bien, ou ça va moins bien – il ne faut pas se laisser trop énerver avec ça. You have to be able to talk, you can't be shy, you have to be able to take a lot of things with a grain of salt and with humour. You have to be able to assess the situation and if it's a good day, which direction to go in, and if it's not a good day, you try to chose another direction. You have to know when to leave... You have to be in tune with what is going on, and when things are going well or not so well – you can't get too excited about that (I7B, 2413-2431).*

Adopting roles. Simone realizes that it is her duty to care for Lucien first because he is her father and second, she believes she is in the best position to do so as she explains:

*Quand qu'on s'implique avec le médecin, quand qu'on s'implique avec la garde-malade, quand qu'il y a eu des petits accrochages on s'en ait mêlé...je fais ça avec mon père parce que c'est mon père et ça fait partie de son paquet – so that's caregiving. Il y a aucun doute. Il y a tous les soins émotionnels, il a les soins mental – mental needs – ça c'est nous autres. Ce n'est pas les autres. Puis ce n'est même pas, je pense, les gardes-malades à un point où ils sont capables de*

*donner ces soins là, parce que c'est nous autres qui le connaît mieux.* When I get involved with the doctor, when I get involved with the nurse, when there are problems, we got involved...I do this with my father because he's my father and that's part of the package – so that's caregiving. There is no doubt. There's all the emotional care, the mental needs – that's us. It's not anyone else. And it's not, I think, the nurses to a point where they are able to give that care, because it's us who know him best (I7A, 2474-2512).

Vignette H – “When are you coming back?” – Antoinette and Edouard (wife and husband)

Antoinette has been visiting her second husband, Edouard, in long-term care for the past year. They see each other on a daily basis. Antoinette appears to be a kind-hearted person who remains by her husband's side. Edouard is an older man who seems to appreciate his spouse's presence, although he can be confused at times. She tells her difficult story with courage.

Getting involved. Antoinette indicates that visits are difficult because: “*Il est dans son petit monde puis il ne peut pas s'exprimer pour s'en sortir.* He's in his little world and he can't express himself to get out of it” (I8, 178-179). Antoinette finds that getting involved is at times difficult for her:

*Puis il y a des journées que j'aimerais pas venir, mais on dirait que c'est différent quand je viens pas, il n'est pas...ils disent qu'il cherche, il regarde partout, puis il devient comme anxieux.* Well there are days that I would rather not come, but it seems that it's different when I don't come, he isn't...they say that he's searching, he looks everywhere, and he becomes anxious (I8, 1011-1017).

Antoinette is encouraged by the way she and Edouard's children got involved in the long-term care setting:

*Quand moi j'ai fait la décision avec sa famille, de faire les démarches pour qu'il soit placé, ça été avec leurs suggestions.* When I made the decision with his family to start the process for him to be placed, it was with their suggestions (I8, 398-401).

Doing activities. Antoinette always starts her visits with a sign of affection.

Edouard is usually happy to see her and embraces her. This makes visits worth it for

Antoinette. Next, she is always concerned with Edouard's clothing:

*Mais quand j'arrive je passe toujours, premièrement ce qu'il porte, j'y jète un coup d'oeil à ce qu'il porte, ce qu'il a dans ses tiroirs parce que son linge sale et tout ça c'est tout mélangé. Je m'occupe de revoir son linge pour être certain que c'est accroché.* When I arrive, I always look at what he's wearing, I take a look at what he's wearing, and what he has in his drawers because his dirty clothes and all that are all mixed up. I spend time going through his clothes to make sure they are hung (I8, 1832-1837).

Antoinette indicates that continuing daily routines is essential to give rhythm to

Edouard's life:

*Bien disons que j'essaye de continuer comme toujours, même que je sais que ça enregistre pas trop là, mais c'est peut-être pas logique pour quelqu'un d'autre, mais je me dis – ça fait quelque chose à faire.* Well I try to continue as always, even if I know that it doesn't register all that much, it might not be logical for someone else, but I tell myself – it gives us something to do (I8, 922-930).

Antoinette is involved in taking Edouard to medical visits, shopping, bringing his favourite apple pie with a margarine container full of ice cream. Often, they play cards for a while and then share a meal. Antoinette describes such a visit as follows:

*Bien des fois je vais l'amener manger, comme j'ai mangé ici avec lui hier soir. Je l'ai amené jouer aux cartes puis là j'ai regardé le menu et tout ça, puis j'ai dit, écoutes, on va jouer aux cartes plus longtemps puis à cinq heures on ira manger ensemble, mais il faut que tu leur (les employées dans la cuisine) dis, alors il s'est levé puis il a été leur dire qu'on allait venir ici pour manger. Mais normalement, je ne mange pas ici trop souvent, je viens le chercher plutôt puis je l'amène peut-être pour du poisson, une pizza ou quelque chose qu'il ne pourrait pas prendre ici.* Well sometimes, I will bring him out to eat, like I ate with him last night. We played cards and then I looked at the menu and all that, and I said, listen, we'll play cards a bit longer and at five o'clock we'll eat together, but you have to tell them (the kitchen staff), so he got up to tell them that we would be eating here. But usually, I don't eat here too often. I'd rather come and get him to go out for fish, a pizza or something that he couldn't have here (I8. 310-323).



Assisting Edouard with activities such as banking is a way of including him in daily life as explained by Antoinette:

*Même quand je vais à la banque, c'est moi qui fait toutes les transactions tout le temps, mais je m'assois avec lui puis je lui explique comme, même si ça reste ou ça ne reste pas, je ne sais pas – je ne sais pas si ça reste, mais je lui dis quand même. Bien il doit se sentir encore conscient que je respecte ça. Even when I go to the bank, I do all the transactions all the time, but I sit with him and I explain things, like even if it sticks or doesn't, I don't know – I don't know if it sticks, but I tell him anyway. Well he must feel like he's still conscious and I respect that (I8, 724-731).*

Antoinette is glad that Edouard still participates in certain routines and rituals.

For instance, she likes it when he helps her out with items that she brings into the long-term care setting:

*Puis comme si je viens, puis j'ai un sac à apporter, disons il me rencontre à la porte – ah bien je vais prendre ça là, bien gentil il veut aider tout le monde, puis il fait encore ça pour moi. And if I come and I have a bag to bring, well he meets me at the door - ah I'll take that, he's kind and wants to help everybody, and he still does that for me (I8, 747-752).*

Experiencing relationships. Involving others in her visits with Edouard makes visits interesting and rewarding, as Antoinette describes:

*Alors ce n'est pas vraiment une visite avec lui, c'est avec tout ce monde là, alors ça fait comme un - un groupe social quasiment, puis ces personnes là, ils me disent, où t'étais, ça fait longtemps que je ne t'ai pas vu. Puis, bien, c'était les Fêtes - bien quand est-ce que tu reviens là. Hier, ils m'ont demandé ça - quand est-ce que tu reviens...je vais être ici demain soir. Ah okay, okay - puis ils viennent me trouver. So it's not really a visit just with him, it's with everybody there, so it makes like a – a social group almost, and those people there, they tell me, where were you, we haven't seen you in a long time. And, well, it was the holidays – well when are you coming back. Yesterday, they asked me – when are you coming back...I'll be here tomorrow night. Ah okay, okay – and they come and find me (I8, 201-211).*

When asked what is satisfying about her visits, Antoinette expresses that it is the interaction with others, whether it be other residents or family members in the long-term care setting or her children and grandchildren. She enjoys observing Edouard's

interaction with her grandson. Antoinette also identifies difficulties associated with including other residents in their visits. For instance, Edouard is not always pleased with the presence of others because he sees it as infringing on his visiting time with his spouse:

*Ça les fait rire, je suppose qu'ils aiment ça, ça fait quelque chose de différent à leur routine. Il aime à jouer sa joute, des fois il devient anxieux si on joue le jeu de solitaire puis on dirait que c'est un petit peu - je ne peux pas dire une jalousie, mais comme il devient frustré, il ne faut pas qu'il y soit trop longtemps, parce que c'est sa visite... Il ne faut pas les garder trop longtemps. Mais, par contre, des fois il va faire des farces, puis il se relie quand même au groupe, il en jouit lui aussi. It makes them laugh, I suppose that they like it, it's something different in their routine. He likes to play his game, sometimes he becomes anxious if we play solitaire and it seems that it's a bit – I can't say jealousy, but like he becomes frustrated, they can't come for too long, because it's his visit... We can't keep them too long. But sometimes he'll make some jokes, and he fits into the group anyway, he also has fun (18, 250-271).*

Antoinette has established a relationship with staff and believes in letting them know when something is not quite right or keeping them informed. For instance when Antoinette and Edouard leave the long-term care setting Antoinette chooses to let the staff know:

*Bien je peux au moins leurs dire où il va être, jusqu'à quelle heure, je pense qu'ils aiment mieux ça aussi. Durant l'été je l'ai amené pour des fins de semaine, on est allé au chalet, puis il aimait ça beaucoup. Well the least I can do is let them know where he will be, and till what time, I think they like that too. During the summer I brought him for weekends to the cottage. He really loved it (18, 685-690).*

She describes her relationship with staff as follows:

*Pas trop, non, pas trop. Pas trop, parce que – bien avec la garde, de temps à autre elle m'a dit que je peux l'appeler et tout ça. Il y avait un groupe pour les familles, mais je n'ai jamais joint, je suis jamais assisté, c'était comme une autre chose à faire, tu sais qu'est-ce que je veux dire. Not too much no. Not too much because – well the nurse, every now and then, she told me that I can call her and all that. There was a group for families, but I never joined, I never assisted, it's like it's another thing to do, you know what I mean (18, 1423-1430).*

Staff depend on Antoinette to learn Edouard's idiosyncratic needs. When things get somewhat difficult for staff, they are relieved when Antoinette is able to be present.

She explains it in the following way:

*Puis moi je peux deviner beaucoup de choses qu'il essaye de dire tandis que les autres n'ont pas le temps ou ils n'ont pas le savoir peut-être.* And I can guess a lot of the things he's trying to say whereas the others don't have the time or the know-how maybe (I8, 1069-1072).

Putting all this in perspective, Antoinette admits that it's not always easy and at time it's even exhausting:

*Il faut changer l'habitude, il faut essayer de comprendre, il faut essayer de deviner, puis il faut toujours essayer de changer les choses pour garder les choses calmes, puis aussi intéressantes que possible. C'est épuisant des fois.* We have to change the routine and try to understand. You have to try to guess, and always try to change things to keep things calm and as interesting as possible. It's exhausting at times (I8, 1193-1198).

Antoinette believes that her children and Edouard's children are a source of support: "*puis ses enfants sont un gros, gros support, c'est fantastique.* And his children are a great, great support, it's fantastic" (I8, 371-371). She also has a close friend with whom she can confide:

*J'ai une amie très, très intime, avec qui on se parle tous les jours, presque. Mais, il y a des choses peut-être que je raconterai pas à tout le monde.* I have a very, very intimate friend, with whom I speak with just about every day. But there are things that I wouldn't tell everybody (I8, 468-471).

Antoinette indicates that her sisters are also a source of support, yet they are also getting older and have issues of their own. At times, the support of others, although intended to be positive, evokes feelings of discouragement. For example, it is insulting to Antoinette when others assess her situation as being positive. The issue here was that they had not walked in her shoes:

*Puis il y a des gens qui m'ont dit, oh he's doing great et tout ça, mais des fois ils ne sont pas avec lui alors ils ne savent pas. And there are people who have told me, oh he's doing great and all that, but sometimes they are not there with him, they don't know (I8, 358-363).*

Acquiring perspectives. Personal continuity is not always easy to maintain for Antoinette and Edouard. Continuity of their marriage is described in the following way:

*Ce n'est plus une intimité entre nous deux, c'est juste la compagnie ou la sécurité peut-être. There is no more intimacy between us, it's just company or maybe security (I8, 1058-1060).*

When looking at all the negative aspects of visits, Antoinette can't help but to express that:

*Ça c'est les affaires négatives, mais on fait le mieux qu'on peut puis c'est lui qui compte par contre...alors j'essaye d'éviter des situations où ça va être un problème, parce que moi je viens frustrée, puis si lui fait une erreur bien il devient bouleversé puis malheureux. Those are the negative things, but we do the best we can and in the end, he's the one that counts...so I try to avoid situations where it will be a problem, because I get frustrated, and if he's made a mistake well he becomes distressed and miserable (I8, 596-598).*

Taking or having the time to visit allows Antoinette's feelings of guilt to diminish.

Antoinette recognizes that it feels good to be needed:

*Mais ce n'est peut-être pas tellement apprécié mais peut-être – oui, en anglais on dit – needed. Well it maybe not really appreciated but maybe – yes, in English we say - needed (I8, 1955-1958).*

Antoinette indicates that most of the time their visits are pleasant, however difficulties arise and a certain reality sets in. She explains one incident as follows:

*Mais normalement, c'est le fun parce qu'il est content de me voir. Puis il a hâte de descendre par exemple, d'habitude. Mais il y a un dimanche que je suis arrivée, puis il avait l'impression que je le sortais comme tous les autres dimanche – je suis arrivée, il était à peu près quatre heures, à peine quatre heures, il n'était pas dans sa chambre. Puis je suis venue en bas, il était déjà assis dans la salle à manger, il était dans sa robe... Well usually, it's fun because he's happy to see me. And he's excited to go downstairs for example, usually. But one Sunday when I arrived – I arrived, it was about four o'clock, barely four*

o'clock, and he wasn't in his room.. And I went down, he was already sitting in the dining room, in his robe (I8, 792-803).

Antoinette is clear about the most difficult part of her visiting experience which is seeing her husband's health decrease:

*Mais quand je vois qu'il y a une petite partie de ça qui s'en va là, c'est comme un autre stage ça. Il y a quelque chose d'autre qui s'en va.* But when I see that a small part is going, it's like another stage. There's something else that's going (I8, 1271-1274).

One of the ways Antoinette is able to express herself is by writing in her journal before she goes to bed to "*je me vide.* Empty my feelings" (I8, 1524-1530). In addition, she uses her sense of humour to explain how she copes with her situation:

*Je faisais des farces, je disais au bon Dieu, bien écoutes là l'assiette est trop petite envoies-moi un plateau, puis je dis, il l'a rempli.* I was joking, I said dear God, well listen now the plate is too small, send me a platter, and I said, He filled it up (I8, 1492-1497).

Adopting roles. Antoinette not only cares for her husband, but for others in her life. Therefore, she really feels like a support person and explains her situation in the following way:

*Alors, you're a support person, but you know, you reach a point where how much support are you – tu cours, puis tu cours.* So, you're a support person, but you know, you reach a point where how much support are you – you're running and running (I8, 1511-1513).

Antoinette recognizes that she must be present for Edouard because: "*il a besoin de quelqu'un, il a besoin de moi.* He needs someone, he needs me" (I8, 1964-1965).

Antoinette feels a need to be there for Edouard. It is about: "*la loyauté, premièrement, puis le sens de satisfaction et je lui donne ce que je peux, aussi longtemps que je peux.*

Loyalty, first, and a sense of satisfaction and I give him what I can, as long as I can" (I8, 1067-1970). Antoinette believes that one needs the following to visit in long-term care:

*Ça prend de la patience, ça prend la compassion, je suppose. Un peu d'humour, pas mal d'humour. Puis du tact aussi...Puis des fois ça prend beaucoup d'énergie que je n'ai pas, alors ça serait les journées où je ne fais pas d'extra.* It takes patience, and it takes compassion, I suppose. A bit of humour, a lot of humour. And tact as well...And sometimes it takes a lot of energy that I don't have, so that would be the days when I don't do any extras (I8, 1841-1847).

Antoinette believes that one really becomes a caregiver as she explains:

*Oh I guess you become a caregiver – period. Tu sais, bien c'est quand même, quand je l'amène au restaurant il y a un stress, mais c'est quand même une sorite que je ne ferais pas peut-être avec une amie, mes enfants peut-être, mais ce n'est pas la même chose. C'est encore pour lui un lien de quelque sorte, aussi longtemps que je peux garder ça avec lui.* Oh I guess you become a caregiver – period. You know, well it's really, when I bring him to the restaurant there's a stress, but it's still an outing that I would maybe not do with my friend or my children maybe, but it's not the same thing. It's still a link of some sort for him, as long as I keep that with him (I8, 1976-1986).

#### Vignette I – “Now a visitor...” – Carmen and Pierre (daughter and father)

Carmen visits her father Pierre on a regular basis. She enjoys visiting her father in the long-term care setting as compared to the difficult experience she and her siblings had when her father was in hospital. Pierre is a quiet man approaching his nineties. He visits with his daughter and enjoys playing cards with her – it's part of their routine. Carmen is a middle-aged woman who is relieved that her father has found a new home. She is bubbly and quite ready to tell me her story.

Getting involved. Visiting for Carmen is “just like visiting him in an apartment, and because we were visiting him for a year, a little bit over a year in the hospital, this is such a treat” (I9, 481-484). Carmen and her siblings are relieved that their father is now in a long-term care facility that they consider to be the “crème de la crème” of nursing homes (I9, 485-486). It is important for them to know that their father can speak French because “he will speak to everybody in French, even if they don't speak French, he

doesn't realize that at this point in his life. And because he was brought up in the French language, this is just super" (I9, 389-394).

Doing activities. Their visits are usually spent "visiting" which involves playing cards "all the time – all the time, and usually make a pot of tea, in the kitchen, we make tea – they go together, cards and tea" (I9, 5-8). For her, visiting is "to do nothing, make a pot of tea and just tell me what did you do today" (I9, 1388-1389). Going out every Wednesday night for supper to Pierre's favourite restaurant is also part of their routine. Carmen and her siblings alternate Wednesdays. This outing was a routine for a year when her father was in hospital. Now:

It's a joke, because everyone in the family – we always look at each other, because we don't want to go – we're sick of it...what we're doing now because we're sick of it, usually only one of us will go – we alternate" (I9, 27-49).

Carmen reminds her father that tomorrow is Wednesday. Pierre is not sure he will be going as it depends on "how he feels." She is surprised at his reaction because he usually looks forward to the outing.

During my time spent with them, they decide to set up for a card game. A round table serves as the card table. Pierre sits on his bed and Carmen sits in his wheelchair. She finds the chair quite comfortable. Some discussion takes place during the card game, however, Pierre concentrates on his game and wins the first round.

After the card game, Carmen takes the time to clean her father's glasses, brush his hair and shine his shoes while they talk about family and reminisce about events from the past. Carmen likes to hear her father reminisce but is not quite certain about these events. She doesn't know what her father is talking about because these events are "before her

time.” Carmen engages in some personal care tasks, however, there are others which she prefers to leave up to others:

Yeah, like I brush his hair and that when I come in, and I prefer not to do the – I’m not sure what the right word is – I don’t want to do any of the intimate, personal things for him at all, that is just not what I want to do. I’ll wash his face, I’ll wash his hands, the upper part of this body, clean his teeth, I’ll wipe his mouth, but... (I9, 648-655).

Carmen believes that it is important for her father to have all the things he wants, such as a T.V., *La Liberté*, which is the Francophone newspaper, the Free Press, and the latest item: a fridge. She explains one of his requests as follows:

The other day I brought him – he wanted to have nuts and bolts... Okay, you see he likes that when somebody comes over, he has something to offer, because people from those days, when you dropped in, it’s always nice to have a little bit of food and a little tea (I9, 705-711).

Experiencing relationships. When Pierre receives other family visitors, Carmen indicates that: “you could just see the twinkle in his eyes because – my father’s children don’t know, we don’t know what he’s talking about, at all. So he talks about things like that, that I don’t know what he’s talking about” (I9, 169-174). With Carmen, Pierre discusses everyday events but he does not remember who has been to see him in the last while. Carmen thinks that it would be a good idea to have a guest book to be able to initiate some conversations and to know who has been to see her father. Pierre seems frustrated that he cannot remember who has been to see him in the last few days.

Carmen is quite satisfied with the staff in the long-term care setting: “they’re all so nice, and they make them do things, which I’m sure if they were alone these people would not do anything, they would sleep most of the time” (I9, 504-508). Although Carmen has a positive assessment of the staff, she is at times reluctant to contact them: “they had given me that number and I don’t like to use it, but I thought well, this time I’ll



use it” (I9, 124-126). She knows that she can talk to staff regarding issues that arise: “I checked with her (the nurse) this week about that , I said to her – what happened to him...I said, okay, that’s good. I said, I just wanted to make sure it wasn’t my Dad” (I9, 320-326).

Carmen relies on her immediate family for support. They have been there for her and are interested in the time she spends with her father: “My family, or my immediate family which is very small, husband and daughter, they always ask me how he is” (I9, 549-551).

Acquiring perspective. Carmen’s main concern at this point in time is that her father’s mind has “really been going down a lot” (I9, 1066-1067). She expresses the need to do some “research on gerontology” because she does not understand “what happens inside” (I9, 1069-1071) She wants to learn more about the aging process as understanding her father’s aging represents a way of being able to be objective about what occurs and knowledgeable on how to cope: “I have to do some more research, just for my own, to understand a little bit more, I’ll never understand a lot of it, but just to understand how they behave” (I9, 1132-1136).

Carmen indicates “as I get older I realize that my opportunity to visit him is limited, he will not be here in five years. It’s not sad, it’s just a fact of life. And what’s good about it is where he is, I mean, he’s lucky to enjoy life” (I9, 1331-1335). Carmen says that her father has a calming effect on her because “he’s slowed” (I9, 1369-1370). She likes to “go, go, go” but recognizes that she cannot do that with her father:

Like he had a doctor’s appointment last week at three-fifteen, and I came here at two, I came up at two, and we were just going to Saint-Boniface, but by the time I did up his shoes or whatever, did the scarf, the coat, and you have to relax in between each of those, we were just on time, so that’s very good, because we’re

going too fast, everything is fast. I get up and I don't know what end is up and I'm driving and I'm sleeping, and you know (I9, 1373-1384).

As Carmen gets ready to leave her father, she explains that:

He's very manipulative...I give him a little squeeze on the shoulder and I'm backing out of the room – Je voulais te dire (I wanted to tell you)...and that's constant. It's like controlling, and he says nothing, he's got nothing to say" (I9, 930-944).

For Carmen, visits are both rewarding and difficult, as she explains: "very rewarding, at times lots of fun, and the bottom-line is sometimes it's very difficult, I have to add that, you know, it's very, very rewarding, and it's not always difficult but sometimes..." (I9, 1726-1730). For Carmen, being involved in her father's life means:

I guess being able to put yourself in that person's position and think what they might life, is really the bottom-line, and that's very hard to do, and it's also very demanding. The old people are, maybe and probably unintentionally very demanding. And I think, they are very hard to understand and I think you need – patience – you need to be patient, you have to really slow down. You can't come in for three minutes, it just doesn't work (I9, 1745-1756).

Adopting roles. "Now a visitor and at the hospital a caregiver", is the response of Carmen who has cared for her father, Pierre, in the community and in the hospital. I spent some time discussing what made it so different in long-term care and Carmen responded: "my father, he's more well, his whole – physically and medically well" (I9, 1773-1774). The long-term care environment seems to facilitate visiting for Carmen and Pierre:

He's definitely well for an 89 year old, which you know, I think he is. Why a visitor as opposed to caregiver – because here I just feel terrific that he's here, I just find him – I'm sure he has moments of depression and I think – I would think, I don't know, that these just come with old age, with realizing where you are at in your life, and what is ahead, like what's tomorrow (I9, 1774-1784).

### Summary

The lifeworld of visitors can be better understood by uncovering the setting in which visits occur, by defining the concept and by exploring the dynamics of the visiting experience. The descriptive account of participants' visiting experiences allowed for identification of the components and elements of visiting as a concept.

## CHAPTER 5

### Putting It All Together

Visiting, as seen in the stories of ten Franco-Manitobans, is a way of being. It is about human lived experience in the long-term care setting. The previous section focused on the “what and how” and “here and now” of human group life. In order to understand people in this particular setting, it was necessary to become familiar with their lifeworlds: to see how visitors made sense of the situations they encountered in their daily routines and how they dealt with these situations on an ongoing basis. This approach involved venturing into their lifeworlds and talking to visitors about their experiences, observing their behaviour and inquiring into their meanings, concerns, and practices. Chapter 5 focuses on discussing the visiting experience utilizing the concepts adapted from Lorenz Dietz et al. (1994).

#### The Framework

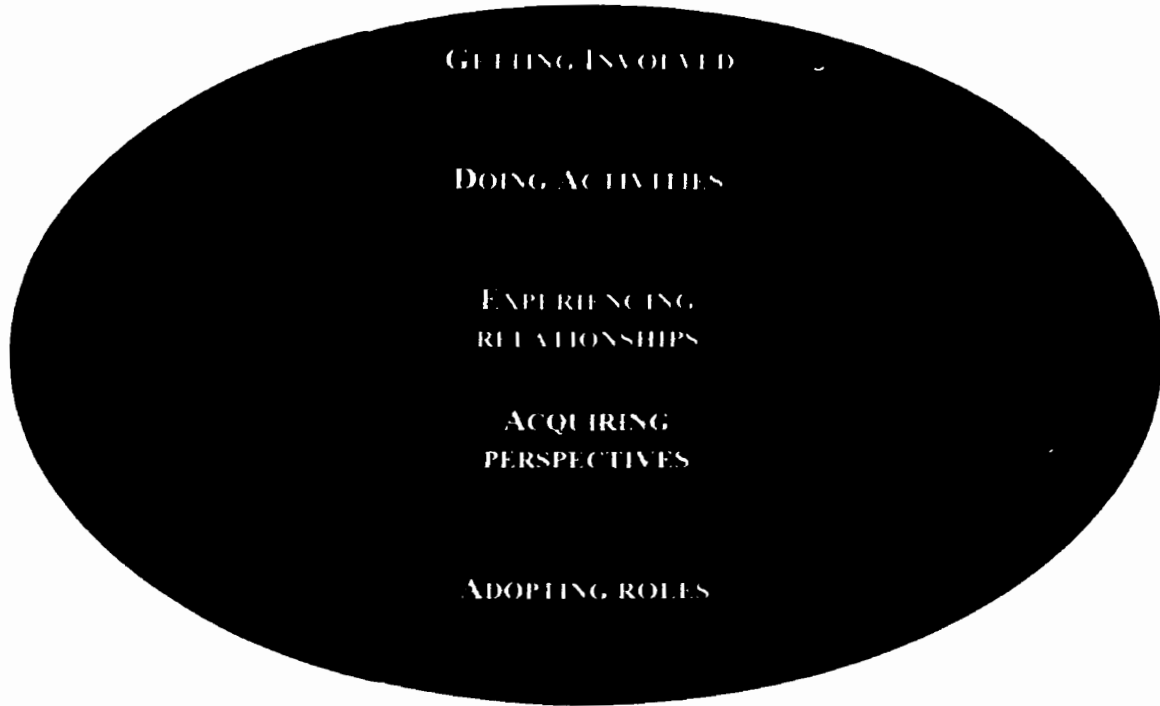
Defining the visiting concept required an application of a data reduction framework to prescribe a means to organize the data. During the later stages of data analysis when transcripts were coded and major categories identified, a framework was found which seemed to fit the data. As data analysis was well underway, it was evident that once adapted the model could earn its way into the study by virtue of its fit and faithfulness to the data. An application of a data reduction framework allowed me to go beyond description and analysis to interpretation of the concept of visiting. Applying such a framework certainly has its limitations. Some data may be found to go beyond the framework. No single or “correct” interpretation of the phenomenon under study exists. Rather, there are multiple ways to arrange and interpret the data. The framework adapted

from Lorenz Dietz et al. (1994) assists in understanding the dynamics of the visiting experience.

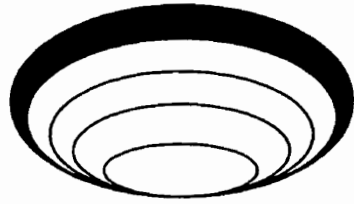
The actual framework developed by Lorenz Dietz et al., focuses on people's participation and experiences in certain aspects of community life. It requires that attention be given to the ways in which people: "get involved; do the activities characterizing that sub-community; develop relationships with the others participating in that setting; acquire perspectives pertinent to that social context; and achieve identities in particular settings" (Lorenz Dietz et al., 1994, p. 57). In the original framework, Lorenz Dietz (1994) refer to "achieving identities." A more appropriate fit for the visiting concept would be adopting roles. An application of this adapted framework allows a better understanding of why visitors get involved; what visitors do; how visitors experience relationships in such a setting; what perspectives visitors have regarding their experience; and what roles visitors acquire in long-term care. I have also developed a conceptual diagram depicting my understanding of the framework (see Figure 4) and its application to the concept of visiting.

The framework adapted from Lorenz Dietz et al. (1994) permits the identification and organization of the common threads across the ten stories and the differences in the various visiting experiences. Figure 5 outlines the components and elements of the visiting experience. The framework was useful as it represented a way to ground social science in the ways in which human lived experience is accomplished. According to Lorenz Dietz et al. (1994):

Figure 4. Conceptual diagram I – Components of the visiting experience

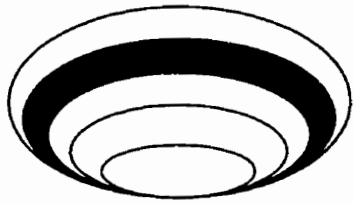


**Figure 5. Conceptual diagram II - Elements of the visiting experience**



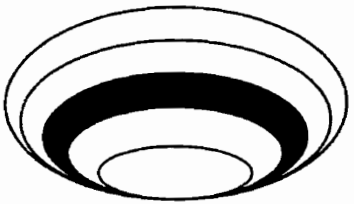
**GETTING INVOLVED**

- PRAGMATIC
- AMBIVALENT
- RESIGNED



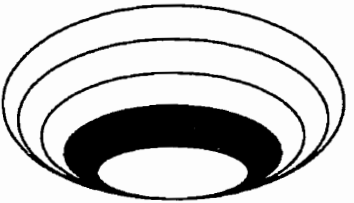
**DOING ACTIVITIES**

- PHYSICAL
- PSYCHOLOGICAL
- SOCIAL
- SPIRITUAL



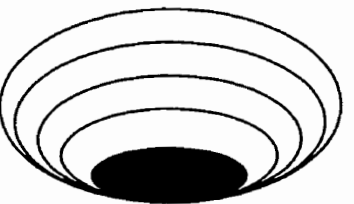
**EXPERIENCING RELATIONSHIPS**

- ACQUAINTANCES
- ASSOCIATIONS
- SOCIAL NETWORKS



**ACQUIRING PERSPECTIVES**

- DANGLING IN THE GRIEF EXPERIENCE
- GIVING RHYTHM TO LIFE
- CREATING A "CHEZ-NOUS"



**ADOPTING ROLES**

- SOCIAL
- MONITORING
- DUTY
- INVOLVED



Rather than destroying the unique features of situations, concepts represent enabling devices for more fully appreciating both the unique and the more common features of situations by providing comparison points for locating and considering particular practices and viewpoints (p. 377).

The framework permits an organization of the knowledge around processes of human interchange and a particular attention to the ongoing and dynamic features of the visiting experience. The components of the visiting experience represent central features of people's associations with one another. The elements help to explain each component. The components and elements of the visiting experience are represented in the form of ellipses to depict process. By process I mean the "linking of action and interaction as they pertain to the management of, control over, or response to a phenomenon:" the visit (Strauss & Corbin, 1990, p. 143). A process may be conceptualized as a "non-progressive movement, that is, as action and interaction that are flexible, in flux, responsive changeable in response to changing conditions" (Strauss & Corbin, 1990, p. 157). The ellipses demonstrate the "emerging, sequencing, unfolding, ongoing features of group life. These concepts draw our attention to the shaping, the forging, the forming, the constructing, the implementing, the *ad hocing*, and the building up of human interaction" (Lorenz Dietz et al., 1994, p. 395). The ellipses portray a process which:

Incorporates the perspectives of the participants, as well as people's capacities for reflectivity, their abilities to influence one another, and their tendencies to develop and act upon particularistic relations with others. This notion of process also encompasses the problematic and uncertain features of group life, the dilemmas people experience and their attempts to come to terms with these (p. 395).

The ellipses offer a heuristic conceptualization for envisioning process in a more concerted fashion. These components are interdependent and need to be viewed holistically if we are to develop a fuller appreciation of each component. Thus, it is



possible to demonstrate that visiting is a whole which is greater than the sum of its parts. Discussion of any one of these components rather inevitably entails some consideration of the other processes. Still, each of these components encompasses elements within, and each is amenable to empirical inquiry.

In the next sections, I explore the dynamics of the visiting experience using the concepts as adapted from Lorenz Dietz et al. (1994). This framework allows for an in-depth exploration of a concept that is assumed to be simple and straightforward, yet is often complex and ambiguous. The next sections consider each of the components of the visiting experience and examine the elements within each component.

#### Getting Involved

Lorenz Dietz et al. (1994) viewed human life as an ongoing set of involvements in social settings where people continuously get in and out of situations involving others. In this study, I was interested in understanding how visitors got involved in the long-term care setting and what characterized their involvement.

“Being involved” denotes the sequencing of people’s participation in settings. It draws our attention to the processual nature of human group life. According to Lorenz Dietz et al. (1994), it gives a “viable and comprehensive sense of what people anticipate as they work their way through settings, how they go about their activities and relate to others they encounter on a here-and-now basis, and how they make sense of, and adjust to the situation in which they find themselves” (p. 345). When exploring the how (versus the why) of involvements, consideration is given to the natural histories of visitors. It is obvious that “people can and do talk about individual involvements and experiences, but participation in the lifeworlds of others entails some interlinkaging of oneself with the

selves of others in the setting” (Lorenz Dietz et al., 1994, p. 57). Thus, it is important to be attentive to the ways in which visitors’ lives intersect with others on an ongoing basis.

Although no question in the interview specifically addressed the placement of an elderly family member in long-term care, most participants expressed their feelings regarding the decision and indicated that it continued to impact their experiences in long-term care. Initiation to the long-term care setting certainly left a lasting impression on visitors as they had vivid memories of this experience. Visitors got involved in different ways, some were pragmatic, others ambivalent and some even resigned.

#### Pragmatic

Some participants viewed their involvement in a very pragmatic way. They were realistic about the resident’s situation and dealt with their involvement in practical terms. For example, Jeanne’s perception regarding her mother’s move to the long-term care setting was as follows: “She was ready, so it wasn’t a struggle – we were even looking forward to it. And she was looking forward to it too, but we didn’t want, and she didn’t want to go anywhere else” (I1, 468-472). These visitors considered the long-term care setting as the best place for their relative at this point in their lives. They welcomed the move to long-term care. Yet, this acceptance was usually not immediate; time was needed to get accustomed to the new setting, to the resident’s situation and to the realization and acceptance of the fact that this was most likely their relative’s last home.

#### Ambivalent

Paul’s involvement was characterized by ambivalence and he frequently spoke about opposing feelings. He was doubtful that the move to long-term care was the best thing for his mother. During the interview Paul had unresolved feelings of guilt and

anxiousness. He fluctuated between believing that his mother should be where she is and believing that she really should live with him and his family. These conflicting emotions affected his involvement. He expressed his ambivalence in the following way: "I think it was a mistake, because I visit her, and I see that her morale is always low. And not only that, I mean, she has changed so much" (I3, 76-85). Later he stated that "Right now, I think that she's probably where she should be and for us, our role as children is to ensure that she is not forgotten and to come and see her often and tell her that we love her" (I3, 529-535).

### Resigned

Some visitors were resigned to accepting their situation. They relinquished the care of their family member to the staff of the long-term care setting although reluctantly. Visitors focused on reconciling themselves to the situation. For instance, when asked about her experience, Dolorès said: "you get used to it." She further explained that this is her life now and reluctantly accepts the situation: "No, no, no. That's my life now, and...it's like, again it's something that has changed in my life and it's become routine. The same thing everyday" (I6, 841-845). For Dolorès, her husband's relocation and her initiation to long-term care represented a difficult situation to accept. For many participants, it was characterized by guilt and sadness. These sentiments were felt because visitors realized that a certain way of life was gone forever. This was often the main reason for these feelings more than institutionalization itself. Visitors were resigned to accepting that their situation and life was never going to be as it was prior to the institutionalization of the resident.

One important point to note is the difference in visiting experiences for spouses and adult children, especially in terms of their initial involvement. Spouses assumed a visiting role, a new role for them, whereas most adult children had already been accustomed to the visiting role prior to institutionalization. As spouses were not visitors prior to the institutionalization of their partners, this represented a turning point in their married life. For spouses, coming every day became a routine and they felt better and experienced less worry than when they did not come. Adult children on the other hand were more confident that things would go on in their absence.

As demonstrated in these excerpts, it is evident that the experience of getting involved varied across participants. Their journeys into the long-term care setting represented a process which had the potential to change overtime depending on the situation at hand. Focusing on this component has demonstrated the need to consider the way visitors got involved in long-term care as it continues to affect their visiting experience.

#### Doing Activities

A second component of the visiting experience is the concept of doing activities.

Lorenz Dietz et al. (1994) described this concept as follows:

People do things in ways that they find meaningful with respect to their notions of perspective and their self-other roles. But, action is much more than that and entails a sense of purposive effort and accomplishment. Further, while people may do things by themselves or in co-ordination with others, it is only within the realm of the intersubjective other that people's activities are meaningful (p. 57).

In adopting this perspective, one must consider the activities associated with visiting to better understand what visitors actually do when they visit and the meaning they attribute to these acts. This component demonstrates how visiting involves "patterns

of symbolic actions which can be organized and understood as cultural performances of everyday life” (Goodall, 2000, p. 116). These patterns can be analyzed as routines, that is, what visitors “do” in long-term care and as rituals in terms of what visitors “do” that counts for them (and also for residents) as particularly and symbolically meaningful.

Visitors facilitated their relationship with residents by engaging in a variety of activities. As demonstrated in the ten stories, visiting is a social act and a vehicle for accomplishing tasks. Once visitors entered the lifeworld of the resident they became involved in aspects of daily living. They were in a world where quality of care and quality of life issues were of great importance. Both long-term care institutions emphasized meeting the needs of residents by “providing individualized care to the elderly and disabled, thus responding to their total needs – body, soul and mind” (Foyer Valade, p. 5). Visitors, as well, strove to meet their relative’s needs. While visiting, family members engaged in a wide range of activities designed to meet the physical, social, psychological and spiritual needs of their relative, often in concert with the staff.

Most visitors shared some personal care with staff such as accompanying the resident to medical appointments, helping with dressing, arranging haircuts, brushing hair, and cleaning teeth. Only a few visitors mentioned engaging in activities such as feeding, toileting, providing supplies, running errands, doing laundry and helping residents participate in activities. Visitors were not usually involved in heavy care tasks such as bathing. Visitors relinquished almost all of these tasks to the staff. Some visitors performed specific tasks as a means of monitoring the resident’s well-being. For others it was clear that they did not want to take part in performing certain tasks. They were reluctant to become involved in these aspects of care for a variety of reasons; residents’

independence, discomfort with intimacy, or fear of performing a specific task for which they would become responsible.

In the interviews, participants emphasized the social aspects of the visiting experience. When asked to describe what they did while visiting, most participants mentioned playing cards or dominoes, watching television, reminiscing, visiting other residents, attending mass, arranging family gatherings, discussing current events, singing, letter writing, enjoying nature and outings for a meal, taking care of finances or visiting other family members. They usually described these activities as a pleasant way of maintaining their relationship with the resident. Visitors indicated that activities such as these enhanced the interactions by giving them something specific to do and talk about.

Despite the emphasis on the pleasant aspects of visiting, participants also identified some challenges encountered during their visits. For instance, participants found their visits taxing when the resident was unhappy or miserable. Some visitors suggested it was unhealthy to discuss the resident's aches and pains during the whole visit. They believed in addressing issues, but changed the subject when conversations focused too much on illness. Having to deal with delicate subjects was another stressful aspect mentioned by participants. Some identified ambiguity regarding their responsibility versus that of staff in speaking with residents about their hygiene or a troublesome behaviour.

Visiting was a vehicle through which visitors performed tasks as needed. Visitors had to spend time in the long-term care setting with the resident to recognize what tasks needed to be done and to perform selected tasks. One visitor clearly stated that he did not see visiting as a task in itself. He further explained that it was not necessary to have a list

of planned tasks to do when visiting in long-term care compared to the community setting. However, he chose to do his mother's laundry to protect his mother's clothes and most importantly to monitor her well-being. As evidenced during the participant observations, most visitors engaged in some tasks. However, visitors said little regarding the tasks they performed and almost no one discussed the division of labour between staff and visitors. This lack of attention to the actual tasks performed resulted in an emphasis on the more social and subjective dimensions of the visiting experience just as in Duncan and Morgan's (1994) study.

Other research examined tasks visitors performed in long-term care by using a pre-determined list of activities (Dempsey & Pruchno, 1993; Schwartz & Vogel, 1990). These studies suggest that frequent visiting provided more opportunities to care for the resident. Most studies, however, do not emphasize the emotional support provided by family members. For instance, in Dempsey and Pruchno's (1993) study, the pre-determined list of tasks only identified one task to represent emotional support. This present study sought to understand visiting in a more comprehensive way by focusing on the routines and rituals which visitors found to be important in visiting. This approach allowed visitors to share their social experiences during visits. The findings of this present study suggest that visitors involved with a resident who has the capacity to consent emphasized socialization and relationship-based activities first, but that a substantial number identified personal care tasks as well.

#### Experiencing Relationships

During the fieldwork, I observed that visitors' experiences were shaped by ongoing social interactions. Who they interacted with when visiting in the long-term care

setting influenced their visits. However, there is much more to people's relationships than simply identifying those with whom they associate. In long-term care as in other settings, "human behavior is relational in its essence" and "people's lives become meaningful only as a consequence of others" (Lorenz Dietz et al., 1994, p. 57). In this study, it was important to pay particular attention to the sorts of "bonds, affiliations, and associations that people develop with one another and the ways in which they work out the aspects of their lives in conjunction with one another" (Lorenz Dietz et al., 1994, p. 57).

As relationships emphasize the intersubjective essence of human lived experience, it is important to consider the ways in which visitors approach others, how they fit their activities together, and how they organize their routines with respect to these sets of others. The others involved included other residents and family members, staff and others outside the long-term care setting. These actors had an important role in shaping a mostly positive or negative visiting experience. Relationships included acquaintances, associations, and social networks.

### Acquaintances

One important factor that seemed to enhance the visiting experience was the contact between visitors and others in the long-term care setting. For many, friendships had been formed or were being formed among visitors, other residents, and other visitors in the setting. These acquaintances represented a source of support for visitors. These social groups, as one participant identified them, usually met in a common area in the long-term care setting. Some visitors preferred to visit in public areas of the institution so that they could meet other residents and spend time with them. Often, a simple contact with others in the institution made visits more pleasant for visitors. These contacts left



visitors feeling good about their time spent in the long-term care setting. Visitors also identified difficulties associated with including other residents in their visits. In some cases, residents was not always pleased with the presence of others because they saw it as infringing on their personal visiting time.

### Associations

Although the interaction between visitors and staff was not the focus of this study, visitors were inclined to discuss this interaction as it affected their visiting experience. Most of the relationships identified between staff and visitors can be characterized as associations as most visitors indicated that contact with staff was limited. Associations allowed visitor and staff to combine for a common purpose and to have dealings when necessary. Interaction with staff ranged from just acknowledging their presence to speaking with them when an issue arose. It was evident that regular contact with staff was quite limited. Some visitors indicated that they stayed out of the way of staff and did not bother them unless absolutely necessary. However, visitors appreciated the availability of staff to interact with and help them solve problems. They also appreciated the contact they did have with staff. In addition, it was important to know that their relative knew the staff well. All in all, visitors felt assured that things would go on in their absence and a sense of confidence in staff and the organization as a whole existed. These findings suggest that some participants had little interaction whereas others had established a rapport with staff. Nonetheless, it was evident that an association existed between visitors and staff regardless of the level of interaction.

The interactions were different and often tense between visitors and staff when an issue had to be dealt with and it was not clear whose responsibility it was. In Jocelyne's

case, for example, she was asked to participate but felt awkward and wanted staff to take care of “it”. She was not comfortable in taking on a specific task. There was reluctance on the part of visitors to address certain issues with staff for fear of saying the wrong thing or being perceived as “demanding”. Some did not address certain issues for fear of tarnishing their relationship with staff or being perceived as demanding by staff because of a particular request regarding the resident.

Studies which specifically explored the nature of relationships between staff and family members (Bowers, 1988; Rubin & Shuttlesworth, 1983; Schwartz & Vogel, 1990; Shuttlesworth et al., 1982) have demonstrated the importance of both formal and informal supports to achieve optimal care for residents. Indeed, most studies examining the role of staff members recognized the overlap in the provision of emotional support by family members and staff, but considered family to be the most important source of this support (Dempsey & Pruchno, 1993, p. 139). As most of these studies emphasized the staff perspective the current study contributes to this knowledge base by presenting the visitors’ perspective.

### Social Networks

Others outside the long-term care setting, especially family members, were a source of social support. Most visitors identified their immediate family as an important source of support. Others had friends with whom they shared their satisfying or challenging experiences in long-term care. These networks provided visitors an opportunity for expressing feelings. However, some were concerned with overwhelming their support persons. At times, the support of others, although intended to be positive, evoked feelings of discouragement. For example, it was insulting to one participant when

others assessed her situation as being positive. The issue here was that they had not walked in her shoes therefore did not understand how bad things really were:

*Puis il y a des gens qui m'ont dit, oh he's doing great et tout ça, mais des fois ils ne sont pas avec lui alors ils ne savent pas. And there are people who have told me, oh he's doing great and all that, but sometimes they are not there with him, they don't know (I8, 358-363).*

These types of interactions must be considered when studying the lifeworld of those who spend time in long-term care. Experiencing relationships is part of the human lived experience in long-term care and has the capacity to shape a mostly positive or negative experience in this setting.

#### Acquiring Perspectives

To more fully understand the concept of visiting it is essential to explore the meaning associated with the visiting experience. In the following section the symbolic meaning attached to the visiting experience will be examined to determine how people act on the world and create meanings. Goodall (2000) explained that “we actively, sometimes mythically, imagine our lifeworlds. Then we walk, purposefully, and dramatically into them” (p. 46). The component of the visiting experience which uncovers the subjective dynamics of the visiting experience is acquiring perspectives.

When trying to understand human group life, it is important to consider the perspectives, worldviews, cultural viewpoints or symbolic realities of participants, as they are known to shape a particular experience. Lorenz Dietz et al. (1994) explained that:

Human group life becomes distinctive as a consequence of the perspectives that develop over time as people interact with one another; it is in this respect that we speak of human behavior as minded, for it is informed by the perspectives shared with others (p. 57).

Understanding the meanings attached to the visiting experience makes it possible to better understand the experiences of visitors. In this study, visitors created meanings to help them make sense of this part of their world. Moreover, actors thought about and acted according to the meanings they attributed to their actions and context. Duncan and Morgan (1994) and Bowers (1988) emphasized that family members of institutionalized older adults are more likely to define their roles in terms of the meaning and purpose they attribute to their roles rather than by the tasks they perform. This study was structured to capture the meaning and purpose of visits from the visitor's perspective. The meanings attached to the visiting experience included dangling in the grief experience, giving rhythm to life, and creating a "chez-nous".

#### Dangling in the Grief Experience

Participants experienced grief in their lifeworlds as visitors. They grieved for the way their relative used to be as well as for the continued losses that their relative experienced as a result of institutionalization, long-term illness and aging. Three factors identified as being part of visitors' grieving experiences were the placement decision, the ongoing physical and mental decline of the resident and the daily and final disengagement. This grieving process involved being aware of what is lost, then adjusting to the reality of that loss.

The institutionalization of a spouse or parent meant adapting to a new reality where visitors experienced relief as well as mourning all at once. Initiation to the long-term care setting certainly left a lasting impression on visitors as they had vivid memories of this experience. For some, both the elderly person and the family welcomed the placement decision. In many cases, decision-making often involved the older person and

was not considered a forced or negative choice. Others continued to feel distraught because of the placement and questioned whether it was the right decision. The distress was evident in some participants' experiences with the long-term care placement. Some had no choice but to accept the fact that this was the way it was going to be.

Placement in a personal care home is often negatively perceived. It is usually not a celebrated event – you go there to die. Lynott (1983) suggested that the placement decision begins with an emotional feeling and that families seek a rational explanation over time. Thus the decision is never made with finality, but is an ongoing event after admission.

While visitors spent time with their relative, they encountered difficulties in terms of dealing with the aging and illness process. The continued physical and mental losses of the resident contributed to the grieving experience. Visitors recognized the ongoing decline in the physical and mental capacity of their spouse or parent. They utilized a variety of techniques to deal with the grief associated with this decline. A few avoided discussing the loss. Some reevaluated the placement decision and others recognized and accepted the decline and the aging process.

Disengagement was an important component in ending a visit. Participants' stories suggested that disengagement involved more than just leaving as strong sentiments were associated with the impending departure. Disengagement was more than just a routine practice to end a visit. For instance, visitors indicated it was important not to leave angry and to engage the resident in the departure ritual. The disengagement experience was made easier because visitors did not have to worry about the residents' safety and well-being once they left. As one participant said:

*Et puis, c'est plus facile ici, c'est bien plus contrôlable. Je ne suis pas obligé - une fois que je pars d'ici j'ai pas besoin de m'inquiéter.* And, it's much easier here, it's much more controllable. I'm not obligated to – once I leave I don't have to worry (I3, 495-499).

The final disengagement associated with death also affected participants. Many visitors spoke of their relatives' readiness to die and acceptance of their eventual death. This perception reassured visitors, yet they could not help but express a continued need for their family member's presence. In a way, visitors continued to sense a need to have their relative in their life. These sentiments are reflected in the following participant's quote:

Oh yeah, no, no, quite often she'll discuss it, and of course telling us we should be ready - You never know when it's going to happen. I guess it's more up front with her because of her age that she does think about it quite a bit (I5, 1052-1057).

#### Giving Rhythm to Life

Shield (1990) characterized the long-term care setting as a place where preparation for death is actively discouraged; religion and ritual are minimal; involvement by the community is meager; and isolation is prevalent. Furthermore, she viewed institutionalization as a rite of passage where residents and visitors experienced a separation from their old status. Specifically, residents experienced a separation from their home and their community setting. Visitors also experienced a separation from a community-based relationship to an institutional one. Residents and visitors also experienced a transition or liminality between their old roles and their new roles. Shield viewed this stage as the most dangerous as residents may sense they have no place in society and both the resident and visitor must restructure their relationship in the context of a new environment. The journey into long-term care requires a transition to a new world. I would argue that this is done by engaging in routines and rituals that give

rhythm to life. Institutionalization involves a serious disruption of life-long social and cultural patterns of interaction. Visitors have an important task in re-creating rhythm to life for themselves and their relative.

In the interviews, visitors described the practices, events, and episodes that were routine performances in their visits. Routines in everyday life help to structure the day and if these routines are interrupted, people notice and respond to them as interruptions (Goodall, 2000). During the participant observations, I noted activities and contexts for actions. These observations provided a record of how everyday practices in long-term care achieved routine. Equally important were ritual practices characterizing the visiting experience. These rituals were anticipated, experienced, and interpreted by participants as important organizing events (Goodall, 2000). During the interviews, participants described what counted for them in their visits and what was meaningful.

Visitors engaged in activities which became normalized because they were repeated time and time again. The activities became routine and the actors came to know what to expect from visits. These routines and practices reduced loneliness, helped in adapting to the aging process, and ensured personal continuity and connectedness.

Visitors in concert with the institutions helped to maintain residents' cultural continuity after institutionalization. This dimension illustrates the importance of maintaining cultural patterns of social interaction in institutional contexts. Sharing symbols and conceptions of reality that are familiar and relevant to the Franco-Manitoban culture helps residents and visitors to cope with this institutionalization.

Franco-Manitoban visitors recognized the importance of providing a sense of ongoing involvement with the outside world for the resident. They were often the link

between the resident's lifeworld in the long-term care setting and the larger community. Visitors did this by: subscribing to *La Liberté* (the weekly Francophone newspaper), ensuring continuity of family traditions (i.e. sharing a meal, having snacks available), reminiscing about family stories, marriages, and family secrets and participating in religious activities. Antoinette, who is Edouard's second spouse, explained it as follows:

Well I suppose it's more – what does he bring to me – it leaves me a sense of continuity, of familiarity and a link with his children, because if all of a sudden I stopped visiting, well it would be empty and the communication with his children wouldn't be the same, because I would have nothing to tell them because they live far away, so I am the key person...so his grandchildren and his children live far away and it's the only way to stick together, I don't know, linked together (I8, 1911-1929).

For visitors, giving rhythm to life was a way of maintaining contact with the resident. It provided routines and rituals to which both the visitor and resident looked forward. Once these routines and rituals were created and established in long-term care, they gave rhythm to life. When visitors spoke of routines and rituals, it was evident that these gave them a sense of purpose and worth which helped them to cope with feelings of sadness, guilt and loss.

Giving rhythm to life highlights strong Francophone cultural markers: the importance of religion, family connectedness, sharing meals, and creating a sense of community within the long-term care setting.

#### Creating a "chez-nous"

When visiting, participants explained that they focused on creating a "chez-nous" and were in the best position to ensure that a sense of "home" was created. Creating a place to call home in long-term care is a dynamic continuous journey for visitors and residents; it does not end when all artifacts and memorabilia are in place. In this study,



visitors took part in the creation of a sense of home, a place where residents could “dwell” and a place where they could spend time. In striving to make this “chez-nous”, visitors focused on comfort and happiness for their relative. The first step in achieving this “chez-nous” was accepting that the long-term care setting was the best environment for their relative at this point:

*Comme c'est là, je pense qu'elle est probablement où est-ce qu'elle devrait être et nous autres, notre rôle comme enfants, c'est de s'assurer qu'elle n'est pas oubliée et de venir la voir assez souvent et lui dire qu'on l'aime.* Right now, I think that she's probably where she should be and for us, our role as children is to ensure that she is not forgotten and to come and see her often and tell her that we love her (I3, 529-535).

Prior to institutionalization, many residents lived in environments where it was difficult to meet their needs. Visitors had difficult pre-institutionalization experiences and had seen their relative in a vulnerable state. For the most part, they were relieved that the resident now had a “safe place” to call home. Visitors were, however, preoccupied with the continuous task of making the long-term care setting a home for their relative.

Recognizing the long-term care setting as “chez-nous” was a first step in creating a place to call home. Residents as well as visitors worked towards accepting this dwelling as home. As one participant said: *“C'est ça, c'est son monde à elle, c'est un nouveau monde. Puis nous autres il faut l'accepter aussi.* That's it, it's her world, it's a new world. We must accept it too” (I1, 823-825). This recognition was also reflected in the language used by participants to describe the long-term care setting. The following comment represents the language used by visitors to describe their relative's “home”:

*“Bien, ce n'est pas un hôpital, c'est son chez eux.* Well, it's not a hospital, it's her home” (I2, 1092-1093). To further support this notion, a recent obituary of a resident from one

of the two long-term care facilities emphasized the importance of the notion of “chez-nous” for Franco-Manitoban families:

She spent her life with her family on the farm; a place she always referred to as her “chez-nous”. Her children were her greatest love...the family would like to thank the staff. Our mother enjoyed her last “chez-nous” and you made her stay a pleasant and comfortable one (Winnipeg Free Press & La Liberté, 2000).

Personalizing the resident’s space helped to foster a sense of home. For some visitors this involved relocating artifacts and memorabilia that were important to the resident. This enhanced the individual’s sense of identity and linked past, present and future. During the participant observations, I noted that residents were proud of these personal items. Many residents appeared pleased to tell me about themselves and the many items in their rooms that represented parts of their lives. Symbols, memorabilia and artifacts in residents’ homes made it their “space”. Religious symbols were common, pictures decorated the walls and many had some candy or food nearby for visitors. These items were often utilized to initiate a conversation as noted in many participant observations.

The institutions also recognized the importance of personalizing space as reflected in policy statements such as “your room is your personal space. You may decorate it as you wish and bring in personal items” (Foyer Valade, p. 11). Achieving an elderly person’s “chez-nous” in an institution was a challenge for many residents and visitors:

There’s lots of times I think you know, she really should be with one of us, where she could have a nice big room for her stuff and more, you know. The hardest part of the whole thing was, she knew that she was coming in here and she wanted to part with her stuff, but found it very, very hard. And she would just sit in a chair and cry, cry, cry. And you know, you try and console her. I would say to her, Mom, it’s still yours, it’s just in a different place and any time you want it, it’s there, if you want to take it back, it’ll be there. If you just want to look at it, it’ll be there, it’s just somebody else looking after it, there’s just no room for it.

So then she would kind of cheer up, but it's got to be a hard thing to do (I5, 837-851).

Despite the challenges, many participants seemed to take comfort by assisting in the provision of a safe, caring, and home-like environment for their elderly family members. The more a visitor perceived that the resident felt at home, the more he or she accepted that the resident's home-life would continue:

*C'est sa chambre, c'est sa maison.* That's her room, it's her house (I2, 382-385).

*C'est ça la différence, si on peut dire avec un foyer comme ça ici – qui est la raison pour être actif, il y a une raison pour ça, pour s'habiller le matin.* That's the difference, if we can say that a home like this – that there is a reason to be active, there is a reason for that, to get dressed in the morning (I2, 884-888).

Researchers support the importance of the notion of chez-nous. For instance, Rowles (1979) argued that:

The creation of an environment in which an older person can function effectively does not make a home, a process involving more than a sensitive architect. Making a home may be facilitated by the transference of artifacts and memorabilia that are important to the preservation of an individual's sense of identity and links to both a past (archival relics of an ancestry and life history) and a future (items to be passed on to future generations to preserve a sense of continuity) (p. 348).

Furthermore, home is a “repository for meaning and personal identity is also enhanced by the presence of artifacts and possessions transferred from previous residences, as these provide tangible manifestations of the individual's past and cues to the resurrection of that past via reminiscence” (Rowles, 1987, p. 348). In this study, visitors provided a sense of ongoing involvement with the outside world by enhancing residential permeability by visiting frequently, accompanying the resident to former homes and neighbourhoods, exchanging letters and telephone calls, and reminiscing with the resident.

Although most participants attempted to create a chez-nous atmosphere, not all participants perceived the attempts as successful. Some participants indicated feeling sad because their relative had experienced the loss of a familiar environment and a lifetime of meaningful possessions. Although participants were positive in their assessments of the institution they visited, most were critical of the idea of institutionalization itself.

### Adopting Roles

The last component used to explain the visiting experience is adopting roles in long-term care. In the original framework, Lorenz Dietz (1994) refer to “achieving identities.” A more appropriate fit for the visiting concept would be adopting roles. Human behaviours involves the formation of roles and this requires a differentiation of self and others. Roles are defined as:

Patterns of behavior, structured around specific rights and duties and associated with a particular status position within a group or social situation. A person’s role in any situation is defined by the set of expectations for his behaviour held by others and by the person himself (Theodorson & Theodorson, 1979, p. 352).

Much of our behaviour involves adopting roles and this requires a differentiation of self and others. According to Lorenz Dietz et al. (1994), “adopting a sense of self requires that one be able to make indications both toward the other and toward one’s own being as an object of one’s own awareness” (p. 57). Adopting a role is about being able to “make indication both towards the other and toward one’s own being as an object of one’s own awareness” (Lorenz Dietz et al., 1994, p. 57). This aspect of human behaviour helps to explain how participants identified themselves and their roles.

In this study, participants defined their visiting experiences in terms of the purpose and meaning they attributed to those experiences. Their lived experiences are presented in this section in the form of ideal-types. According to Max Weber (1946) an ideal-type

is a methodological technique for organizing certain elements of reality into a logically precise conception. It is a useful concept for understanding the complexities of the lifeworld of visitors in the long-term care setting and the roles they adopt.

Weber reduced social phenomena to their core components by “singling out and accentuating the central or basic features... and suppressing or downgrading those features that could be considered marginal” (Parkin, 1982, p. 28). Consequently, an ideal-type is unlikely to be an accurate representation of the real thing and is not meant to correspond exactly to any single empirical observation (Theodorson & Theodorson, 1979). Weber used the concept of an ideal-type to study capitalism, bureaucracy and world religions. He argued that “such patterns of behaviours and institutional forms are each composed of a large number of interconnected elements and in order to comprehend any such institution or social formation it is necessary to reduce it to its core components” (Parkin, 1982, p. 28).

It is useful to consider the concept of visiting in the context of ideal-types to better understand how visitors adopted roles in the long-term care setting. Ideal-types do not conform exactly to the features of any one particular visitor; rather, they are a “distillation of the principal features that are characteristic” of visitors in general (Parkin, 1982, p. 29). In other words, an ideal-type only approximates social reality. It “does not describe an individual course of action, but a ‘typical’ one – it is a generalized rubric within which an indefinite number of particular cases may be classified” (Parsons, 1947, p. 30). Visitors in this study adopted social, monitoring, duty and involved roles.

### Social Role

For some participants, the primary focus of their visit was social. The point of the visit was to spend time together. The visitor and visitee engaged in dialogue and activities that made a visit a social event. Most studies in long-term care suggest that social interaction is important for residents, yet few have focused on the benefits of social visits for visitors. For instance, Arling et al.(1986), Greene and Monahan (1982) and Harel and Noelker (1982) all support the notion that maintaining elderly people's ties with their family and friends after they enter long-term care enhances their life satisfaction, morale, and sense of personal control. Some studies recognized the benefits of spending time with residents, yet most focused on the burden experienced by visitors. In this study, it was evident that during social visits, visitors recognized the importance of continuing ties. For some, social visits were difficult especially if the past relationship was strained and if the resident's health was declining. Yet, in some cases social visits improved the relationship between the visitor and the resident as depicted in Jocelyne and Madeleine's story. These types of visits were beneficial to both the visitor and the resident. Social visits were valuable to the resident as they "served as a tie with their own past and also provided a link with the world beyond the long-term care setting" (Dempsey & Pruchno, 1993, p. 144). In these types of visits, much of the focus was on maintaining connectedness. Like the participants in Friedemann et al.'s (1996) study, visitors in this present study emphasized connectedness and focused on the emotional and social needs of the resident.

### Monitoring role

As depicted in the vignettes, some visitors adopted a monitoring role to oversee the resident's quality of care and quality of life. These visitors had various motivations

for doing so. Some felt guilty regarding their inability to care for their relative in the community and hence were motivated to ensure that staff provided the best possible care. Others were motivated by a sense of compassion for their relative. They wanted the care to be of the highest quality and they wanted their relative to continue as an active member in society. Adopting a monitoring role often resulted in a sense of reassurance for visitors and they indicated having a sense of control over the environment. Indeed, some studies have concluded that family members often “held themselves responsible for monitoring and evaluating the effectiveness and quality of caring tasks” (p. 363).

#### Duty role

For some visitors, involvement with the resident was simply a duty, motivated by guilt and love and perceived as a burden to be endured. As depicted in the vignettes, some residents were placed in long-term care after all other resources were exhausted. Although visits were not particularly pleasant in some cases, visitors continued their routines and rituals out of duty. Dempsey and Pruchno (1993) found that many families were at a loss to know how to engage their relative. They did not know what to say or do in the often alien environment of the long-term care facility. General conversation did not usually work. In response to this situation, it is important to help families focus on engaging in activities together with their relatives. In these visits, engagement in non-technical tasks such as managing money, shopping, or adding extras to the residents' room seem to reduce awkward silences and general discomfort and provide some structure to the visit. As Brody (1990) suggested, “still being able to be useful to the parent or spouse may support the feeling of continuing to fulfill one's responsibility and

mitigate to some extent the sense of guilt so many children have when a parent is institutionalized” (p. 216).

### Involved role

Spouses adopted an involved role in long-term care and the main focus of their visits was to provide care. It represented a continuity of their role as wives and care providers. They were as involved as ever in the care of their partner. It was evident that spouses experienced stress during their daily visits and that others, such as doctors, suggested that they diminish their daily contacts. However, they were not able to do so without experiencing feelings of guilt and sadness. Yet, it has been found that people’s health may be a barrier to visiting especially for spouses who may also be suffering from poor health themselves (Harper & Lund, 1990). Similarly to Ross’ (1997) study, I found that spouses did not discriminate between technical and non-technical tasks, that is, they simply provided “care”. These ideal-types served to provide a way to best describe the roles visitors adopted depending on the situation at hand.

### Summary

The descriptive account of participants’ experiences and the identification of relevant themes contributed to a better understanding of the visiting experience. The findings represent the multidimensional and complex nature of visiting in long-term care. The many facets associated with visiting: how visitors got involved; what they did; how they experienced relationships; what perspectives they acquired; and what roles visitors adopted in long-term care suggest that the visiting experience is greater than the sum of its parts. Visiting is an important part of many people’ lifeworlds as it is a way of being and it gives visitors a sense of identity.



## CHAPTER 6

### Summary and Conclusion

The purpose of this focused ethnography was to better understand the lifeworld of persons who visited kin in long-term care and to determine what influenced that experience. The thesis began with an introduction which explained my interest in exploring life in long-term care. This was followed by an explanation of the study's purpose and significance. Research questions were elaborated and the study's conceptual framework was explained. This focused ethnography assumed a symbolic interactionist approach to study visiting which proved to be useful. It permitted a focus on the ways in which visitors did things and worked things out with others. The use of symbolic interactionism as a framework allowed for a detailed account of how visitors viewed their lifeworlds, defined themselves and others, became involved, conducted their activities, and developed relationships.

Chapter 2 presented a literature review focusing on the significance of visiting, the factors influencing visiting patterns, the nature of visits and the relation of culture to aging. Essentially, the literature review established that family involvement is important for residents of long-term care facilities as it provides a "vehicle for the continuation of relationships" (Ross, 1997, p. 67). It also demonstrated that several studies have addressed the continuation of family relationships after institutional placement (Montgomery, 1982; Smith & Bengtson, 1979; Stull et al., 1997). It became evident that no particular term was used consistently to describe family members' involvement in long-term care. Additionally, this review of the literature established that most studies examining family involvement have utilized a predetermined list of tasks and have

explored family members' or staff's expectations regarding the tasks visitors should perform. Hence, researchers often call for an understanding of the meaning of visiting to comprehend task performance. It was evident that a minimal amount of research examined the actual visiting experience of family members in the long-term care setting and the meaning they attached to their experiences.

A qualitative approach to the inquiry was considered to be the most appropriate means of better understanding the perspectives, practices, dilemmas, and interchanges of visitors in long-term care settings. Chapter 3 elaborated the qualitative design of this study which drew specifically on the tenets of ethnographic research. Such a research design provided an opportunity to discover people's lived experiences. The method selected was focused ethnography and lent itself well to the study of visiting as a cultural experience within a Francophone context.

The 9 residents and 10 visitors who participated in this study were related by blood or marriage, had the capacity to consent, identified themselves as Franco-Manitobans and spent time together. Visitors ranged in age from 46 to 68 years. Most visitors were women: six daughters and two spouses. Two of the participants were sons. Six visitors were retired and three were employed outside the home while one was not employed. Most visitors resided approximately fifteen minutes from the institution while one resided more than an hour away. Visitors' social support networks consisted of immediate family members or siblings. Some identified friends as part of their social support network.

Residents ranged in age from 68 to 90 years. More than half of the residents were female (5 out of 9). All of the women were widowed, two of the men were married and

two widowed. Time in long-term care varied from 2 months to 54 months. Most residents had lived in an apartment prior to entering the long-term care facility while one had been hospitalized for over a year and the other had lived in a house prior to institutionalization.

Chapter 4 focused on better understanding the lifeworld of visitors by first setting the context of visits. It is evident that visiting, just like any other social phenomena, is embedded in specific contexts, therefore, considering the settings in which visits took place was important, as most of the empirical investigations to date have rarely considered the setting in which families were involved. Defining the visiting concept required an examination of some assumptions about normative situations in which visits take place. Understanding the visiting experience necessitated a further exploration into the lifeworld of visitors and this required an examination of the components and elements which shaped the visiting experience in long-term care. Vignettes were presented to explore the dynamics of the visiting experience.

Chapter 5 provided an in-depth analysis of the vignettes presented in the previous chapter using the framework adapted from Lorenz Dietz et al. (1994). This framework was useful in putting the data together in an organized fashion to answer the research questions elaborated in the first chapter. The application of the framework captured some of the day-to-day tone and texture of the visiting experience.

To define the concept of visiting and to understand the dynamics of the visiting experience, it was essential to examine what visitors actually did when they visited and to identify the functions, components and elements of visits. The participants' stories provided evidence to suggest that visiting in long-term care is about getting involved,

doing activities, experiencing relationships, acquiring perspectives and adopting roles in the long-term care setting. Findings from this study suggest that visitors in long-term care settings define their visiting experiences as having purpose and meaning. Contrary to much of the literature, visitors consider visiting to be a social act which has the capacity to allow visitors to “care” for residents and to effectively continue relations.

Exploring the dynamics of the visiting experience from the visitors’ perspective allowed for an understanding of the subjective dynamics of visiting and the identification of the opportunities and challenges experienced by visitors. To address some of the gaps in the literature, this study relied on qualitative methodology, specifically, the method of focused ethnography. The techniques of data collection allowed me to observe and participate in visits and engage in discussions with respondents. In this way, I was permitted a glimpse of the visitor’s lifeworld and this allowed me to gain knowledge about the visiting experience in long-term care from the visitor’s perspective. The method of focused ethnography allowed me to explore dimensions which are not often the focus of studies in long-term care. For instance, rather than imposing a task-based definition of the experience in long-term care, this method allowed the respondents to define the visiting experience as they perceived it. By comparing case to case and concept to concept, I became sensitive to the differences and similarities in the experiences of different participants. This process allowed for an analysis which remained faithful to the experiences of visitors.

This study provided a better understanding of the specific experiences of Franco-Manitobans who visited kin in a long-term care setting by examining what form visiting took in a Franco-Manitoban context. The present study included a cultural component

often ignored in studies of long-term care. Participant observations and in-depth interviews facilitated the acquisition of knowledge regarding the Franco-Manitoban culture, its philosophical, religious and family roots which influenced the visiting experience in the long-term care setting. This study illustrated the importance of family connectedness for visitors. In particular, many visitors expressed feelings of guilt and sadness when residents could no longer participate in family traditions. It also highlighted the importance of participating in religious and meal-time activities. Participants were also found to focus on creating a place to call home for both themselves and the residents. This notion of “chez-nous” can be viewed as a concept which is important to Francophones as it is explored in other studies such as Lahaie’s (1998).

Research has demonstrated that family members perceive themselves and are perceived by others in various ways in long-term care settings. In fact, no particular term is used consistently to describe family members’ involvement. To address such variations, Gubrium (1995) argued for a “deconstructive examination of the taken-for-granted language of caregiving, of the concepts and related objects of research that are assumed to specify what the research is all about in the first place” (p. 268). In essence, a critical examination of the term “caregiving” was required. Consequently, this study examined the relationship between visiting and caregiving to determine whether visitors differentiated between visiting and caregiving. The findings of this present study suggest that family members do not utilize one specific term spontaneously to identify themselves in the long-term care setting. No term seems to be able to capture exactly what family members do in long-term care. Their experiences are much deeper and more complex than simply identifying them as visitors or caregivers. The roles they adopted seemed to

better depict their lifeworlds at specific points in their journey in the long-term care setting. Adopting new roles allowed visitors to reconstruct their self-other identities and to be valued for making a useful contribution in their relative's life and to long-term care.

It is important to understand the roles adopted by visitors as they not only assist visitors in understanding their lifeworld but also help enhance the relationship between staff and visitors, ultimately improving the quality of life for residents. Anxiety was certainly experienced when visitors interacted with others whether it was with other residents, family members, staff, or those outside the long-term care setting. It is essential to recognize these challenges in order to facilitate their interactions. Effective collaboration between family and professionals depends not so much on shared tasks and functions as on shared perspectives and understandings of the invisible work involved in visiting.

Exploring the visiting of family members in long-term care settings by kin is an area of significant policy relevance given its implications for the quality of life of residents (Minichiello, 1989). This study provides some recommendations for policy and practice. Results of this study suggest that visits in long-term care produce benefits for the visitor and as such should be encouraged and facilitated through practice and policy. Providers of long-term care must recognize that visitors play an important role in the lives of residents and that by supporting emotional ties outside the long-term care setting, staff can help to maintain and strengthen old bonds of affection, and discover residents' idiosyncratic needs through visitors. Staff are often challenged in facilitating quality of life for residents of long-term care facilities and visitors can be major allies in meeting the needs of the resident as they are often the experts on the needs, values and expectations of

residents. Visitors are also key players in normalizing residents' last years of life by giving rhythm to life and creating a "chez-nous." The presence of visitors in long-term care is essential as it enables staff to see residents in a family context which in turn has the potential to instill respect for residents by reminding staff that residents played previous roles. As a result of these findings, support should be given to staff through education sessions which assist them understanding and accepting the important roles that visitors play in the long-term care context. Findings can also be used to prepare new visitors for the long-term care setting. Participants in this study provided insight into the lifeworld of visitors that can help others gain a greater measure of understanding of the visiting experience.

The vignettes certainly depicted individual variations in the participants' stories. The variability in stories and the possibilities that the long-term care setting can accommodate these unique situations highlights the importance of increasing people's awareness of the ways in which family members visit and attribute meaning to their everyday life. The focus on the different roles adopted by visitors can provide staff with a way of differentiating visitors. These findings suggest the importance of facilitating the interaction between visitors and staff. Routines and policies should make staff more accessible and facilitate communication between the families and staff who share the care of the residents. Institutional policies must encourage and support family involvement in long-term care to recognize the contributions of visitors as participants definitely indicated a need and desire to continue caring in the long-term care context.

In summary, this study contributes to the sparse literature on visiting in the long-term care setting and provides a balance for the studies which emphasize problems and

pathology. Most importantly, it adds to the limited information on the subjective dimensions of visits, thus addressing the need identified by Dupuis and Norris (1997) to consider the subjective dimension, that is meaning, expectation and behaviour of family members involved in long-term care. Furthermore, it contributes to the development of a definition of visiting in long-term care and to the identification of visiting components and elements. Finally, this study sheds some light on the relationships that Franco-Manitobans have with aging family members.

#### Research Issues

Although the study focused on two particular groups of visitors, spouses and adult children, the understanding generated from it has contributed to the development of a framework that serves to better understand the visiting experience in long-term care. This sample is limited as it does not include other visitors, such as grandchildren, friends, or siblings. The difference between the findings of this study and those of other studies, may, in large part, be due to the fact that the current sample was limited to visitors who spent time with residents who were able to consent to the research, whereas most of the participants in other studies were family members involved with participants who had relatively advanced dementia. Another factor affecting the outcomes may be that most participants were regular visitors and had relatively positive experiences. Staff would likely not have recommended those person's whose visits were strained and they themselves might not have been willing to participate.

Additionally, the effect of a researcher sharing the same culture as participants is not entirely clear. However, my experience was that being of the same culture was an advantage especially when participants could determine a social connection. It was



definitely useful for building rapport with participants. Conducting the research in the preferred language of participants was certainly useful as more than half of the visitors chose to speak French during the interviews and most observations took place in a French context. Residents in particular felt most comfortable using their first language.

Conducting a series of interviews and participant observations provided opportunities for data triangulation, for ongoing observations, and for member-checking. Being a participant-observer involved an interweaving of observing, listening and asking questions. This method of data collection allowed me to observe and then ask questions regarding the situation. Being an active observer was useful as it allowed me to ask questions, carry on informal and formal conversations and interact at strategic moments. In this way, I was immersed in the lifeworld of the participants.

Future studies might consider interviews with residents so that they may have a voice. Their perspective would be useful in developing programs for visitors which would take into account what residents expect from visits in order to make the visiting experience more beneficial and effective. It would also be useful to study the experiences of visitors who spend time with residents with cognitive impairments. Although much is known about staff's view of their work in general (e.g., Savishinsky, 1991), less is known about their views on working with families (Duncan & Morgan, 1994). Hence, it would be useful to uncover staff's perceptions regarding visitors' involvement in long-term care.

### Conclusion

The ethnographic research design of this study enabled me to develop an in-depth view of institutional life that captured some of the tone and texture of visitors'

experiences. This study examined the content and aspects of visitors' experiences in the long-term care setting.

Undertaking an ethnographic study to better understand the experiences of Franco-Manitoban visitors to the long-term care setting proved to be a worthwhile undertaking. No amount of reading or discussing can prepare us entirely for the satisfactions, challenges, and anxieties of being in the field. The research experience has been a challenging and rewarding one. There were lulls and peaks throughout the experience, from searching for a manageable research question to wondering whether enough visitors and residents would agree to participate in the study. Certain issues seemed to preoccupy my thoughts more than others, especially the concern of translating the experiences of visitors in two ways. First, being able to translate from French to English and second, being able to uncover what visitors experienced in order to ensure that participants' experiences were accurately represented. The translation from French to English proved to be another way of analyzing the transcripts as it provided an opportunity to really understand what visitors were saying. Although the translation process was taxing because of the time and energy needed and also because of the potential loss of meaning, it proved to be useful in getting me closer to the data. Finally, this study was rewarding because it is grounded in the lived experiences of people and this helped to heighten my appreciation of the world of the other.

In conclusion, this study of visiting experiences in the long-term care setting has been valuable in defining the visiting concept, exploring the dynamics of the visiting experience, and adapting Lorenz Dietz et al.'s (1994) framework to better organize and

understand the components and elements of the visiting experience. This study contributes to a general understanding of the visiting experience that is useful for visitors, service providers, researchers and policy makers.

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APPENDICES



## Appendix A

Letter to Executive Director

Micheline St-Hilaire  
Winnipeg (Manitoba)

Le 14 mai 1999

Monsieur Francis LaBossière  
Directeur général  
Centre Taché  
185, rue Despins  
Winnipeg (Manitoba)  
R2H 2B3

Monsieur,

Par la présente, je tiens à vous remercier du temps que vous m'avez accordé le 27 avril dernier. Suite à notre conversation, j'aimerais savoir si vous auriez l'obligeance de m'accorder l'autorisation d'effectuer une recherche de thèse au Centre Taché et au Foyer Valade. Ma thèse s'intitule : *Visites : expériences vécues par les Franco-Manitobains qui rendent visite aux membres de leur famille dans les établissements de soins de longue durée.*

Je vous fais parvenir un résumé bilingue d'une page de mon projet de recherche, ainsi que le document soumis au *Faculty of Human Ecology Ethics Review Committee* qui fut accepté le 3 mai dernier. Je serai disponible le 21 juin 1999 pour présenter ce projet au Comité d'éthique du Centre Taché/Foyer Valade.

Je souhaite vraiment pouvoir effectuer ma recherche au Centre Taché et au Foyer Valade. Pour de plus amples renseignements, n'hésitez pas à communiquer avec moi au # de téléphone, ou avec ma conseillère de thèse, M<sup>me</sup> Nancy Higgitt, au # de téléphone.

En vous remerciant de prêter attention à ma demande, je vous prie d'agréer, Monsieur, l'expression de mes meilleurs sentiments.

Micheline St-Hilaire

Appendix B

Letter of Approval from Long-Term Care Facility



185, Despins, Winnipeg (MB) R2H 2B3  
Tél. (204) 233-3692 • Fax (204) 233-6803



450, chemin River, Winnipeg (MB) R2M 5M4  
Tél. (204) 254-3332 • Fax (204) 254-0329

Le 22 juin, 1999

Mme Micheline St-Hilaire  
205, rue Kitson – Appartement D  
Winnipeg, Manitoba  
R2H 0Z4

Chère Micheline,

Je viens par la présente te remercier pour ta présentation de ta proposition de recherche dont tu as partagé avec le Comité d'éthique Centre Taché/Foyer Valade le 21 juin.

Le Comité avait plusieurs questions et était très satisfait des réponses fournies à ce temps-ci. Le Comité te félicite pour une présentation et une proposition très bien élaborée et très bien pensée. C'est avec plaisir que je peux t'accorder permission de procéder avec ta recherche.

Prière de rencontrer avec moi afin de discuter davantage qui devrait être la personne contacte à l'intérieur de chaque établissement pour que tu puisses débiter ta recherche.

Veilles agréer, chère Micheline, l'expression de mes sentiments les plus distingués.

Le Directeur général,

  
Francis LaBossier

/dpw

cc: Doris Alarie  
Bernard Lambert

## Appendix C

### Letters to Potential Participants – Residents

Dear Resident,

My name is Micheline St-Hilaire. I am a Master's student in the Department of Family Studies at the University of Manitoba. I am conducting a study about the visiting experiences of Franco-Manitoban family members at Foyer Valade during the summer and fall of 1999.

#### **Description of study**

For my study, I will be conducting interviews with visitors and observations with residents and visitors. I need participants who are related by blood or marriage to a resident who has the capacity to consent, identify themselves as Franco-Manitoban and spend time with their relative. Your participation in this study may contribute to an increased understanding of the visiting experience for professionals in long-term care and visitors and residents may benefit indirectly through an increased recognition of the benefits of visiting kin in long-term care settings. Please note that Foyer Valade as well as the Faculty of Human Ecology Ethics Review Committee of the University of Manitoba have given me permission to conduct this study.

#### **Procedures**

I invite you to assist me in my research by agreeing to let me interview one of your visitors so that I might learn more about the nature of the visiting experience. If you decide to participate I will speak with your visitor for about one to two hours in a location of their choice. During this time, I will ask them questions about their visiting experience. The interview will be tape recorded with the visitor's consent to facilitate the analysis of the information provided. At a later date, I invite you to assist me in my research by agreeing to let me observe a visit between yourself and your family member to learn more about the visiting experience. The observation will last the length of your visit, but no more than two hours.

#### **Voluntary Participation**

Please note that your participation is entirely voluntary and will in no way affect the care that you are receiving, or the care that you will receive in the future whether you agree to participate or not. You may end the observation at any time and you may choose not to answer any question or withdraw from the study at any time.

#### **Confidentiality**

Your identity will remain confidential and will be known only to my advisor, Dr. Nancy Higgitt, from the University of Manitoba, Department of Family Studies, and myself. My thesis committee, namely Dr. Nancy Higgitt, Dr. John Bond and Dr. David Gregory, will only have access to the coded transcripts. No one reading the results will be able to identify you. The information that you share with me along with other resources will be used to complete my thesis research. The study may be submitted for publication in an academic journal.

I hope that you will participate. Please feel free to call me at # or my thesis advisor, Dr. Nancy Higgitt, Department of Family Studies, University of Manitoba at # if you have any questions. If you would be willing to participate in this study, please contact Réjeanne Bérard, social worker at Foyer Valade. Please give her your phone number so that I may contact you to arrange a convenient time for us to meet. Thank you for your consideration.

Micheline St-Hilaire

Cher résident, chère résidente,

Je m'appelle Micheline St-Hilaire et je suis candidate à la maîtrise au *Department of Family Studies* de l'Université du Manitoba. J'effectuerai une recherche au cours de l'été et de l'automne 1999 portant sur l'expérience des membres des familles franco-manitobaines qui visitent un membre de leur famille au Foyer Valade.

#### **Description de la recherche**

J'effectuerai cette étude au moyen d'entrevues auprès des visiteurs et d'observations auprès des résidents et des membres de familles. Il me faut donc trouver des personnes apparentées, par alliance ou par le sang, à un résident ou à une résidente pouvant donner son consentement, qui se disent Franco-Manitobaines, et qui ont l'habitude de venir passer du temps avec ce résident ou cette résidente. Votre participation pourrait contribuer à une meilleure compréhension de ce type de visite par les professionnels, les visiteurs et les résidents de ce genre d'établissement. Veuillez noter que le Foyer Valade, ainsi que le *Faculty of Human Ecology Ethics Review Committee* de l'Université du Manitoba ont consenti à ce que j'effectue cette recherche.

#### **Procédure**

Je vous prie de m'aider dans ma recherche en acceptant que je fasse une entrevue auprès de quelqu'un qui vous rends visite, afin que je puisse en apprendre davantage sur la nature des visites à une personne résidant dans un établissement de soins de longue durée. Si vous acceptez, j'aurai une entrevue d'une à deux heures avec votre visiteur à un endroit de son choix. Les questions porteront sur ce qui se passe lors de vos visites. J'enregistrerai l'entrevue avec la permission de votre visiteur afin de faciliter l'analyse de l'information qu'il me fournira. Je vous demanderai plus tard la permission d'observer une de vos visites avec votre membre de famille, afin de me renseigner davantage sur cette expérience. L'observation durera environ une à deux heures.

#### **Participation volontaire**

Veuillez noter que vous êtes tout à fait libre de participer ou non, et que votre choix n'aura aucune conséquence sur les soins qui vous sont prodigués, maintenant ou plus tard. Vous pouvez mettre fin à l'observation en tout temps et choisir de ne pas répondre à l'une ou l'autre des questions ou vous retirer, en tout temps.

#### **Confidentialité**

En aucun cas je ne révélerai votre identité, sauf à ma conseillère de thèse, M<sup>m</sup>c Nancy Higgitt du *Department of Family Studies* de l'Université du Manitoba. Les membres du jury qui évalueront ma thèse, c'est-à-dire M<sup>m</sup>c Nancy Higgitt, M. John Bond et M. David Gregory, n'auront accès qu'à la transcription des entrevues. Aucun lecteur de ce document ne sera en mesure de vous identifier. Les renseignements ainsi obtenus serviront, en conjonction avec d'autres ressources, à compléter ma thèse de maîtrise. Il se pourrait que les résultats soient publiés dans une revue spécialisée.

Je souhaite que vous acceptiez de participer à cette recherche. Pour de plus amples renseignements, n'hésitez pas à communiquer avec moi au #, ou avec ma conseillère de thèse, M<sup>m</sup>c Nancy Higgitt du *Department of Family Studies* de l'Université du Manitoba au #. Si vous acceptez de participer à la recherche, veuillez communiquer avec Réjeanne Bérard, travailleuse sociale au Foyer Valade. S'il vous plaît lui donner votre numéro de téléphone afin que je puisse vous rejoindre pour prendre rendez-vous. En vous remerciant pour l'attention que vous porterez à ma demande, je vous prie d'agréer, Monsieur, Madame, l'expression de mes sentiments distingués.

Micheline St-Hilaire

## Appendix D

### Letter to Potential Participants – Visitors

Dear Potential Participant,

My name is Micheline St-Hilaire. I am a Master's student in the Department of Family Studies at the University of Manitoba. I am conducting a study about the visiting experiences of Franco-Manitoban family members in long-term care settings during the summer and fall of 1999.

#### **Description of study**

For my study, I will be conducting interviews and observations and need people who are related by blood or marriage to a resident who has the capacity to consent, identify themselves as Franco-Manitoban and spend time with their relative. Your participation in this study may contribute to an increased understanding of the visiting experience for professionals in long-term care and visitors and residents may benefit indirectly through an increased recognition of the benefits of visiting kin in long-term care settings. Please note that Foyer Valade as well as the Faculty of Human Ecology Ethics Review Committee of the University of Manitoba have given me permission to conduct this study.

#### **Procedures**

I invite you to assist me in my research by agreeing to be interviewed by me so that I might learn more about the nature of the visiting experience. If you decide to participate I will speak with you for about one to two hours in a location of your choice. During this time, I will ask you about your visiting experiences with your family member. The interview will be tape recorded with your consent to facilitate the analysis of the information you provide. At a later date, I would like to have the opportunity to observe a visit between yourself and your family member to learn more about the visiting experience. The observation will last the length of your visit, but no more than two hours. Please note that you may choose to have the interview in either French or English.

#### **Voluntary Participation**

Please note that your participation is entirely voluntary and will in no way affect the care that your family member is receiving, or the care that they will receive in the future whether you agree to participate or not. You may end the interview or observation at any time and you may choose not to answer any questions, have the tape recorder turned off or withdraw from the study at any time.

#### **Confidentiality**

Your identity will remain confidential and will be known only to my advisor, Dr. Nancy Higgitt, from the University of Manitoba, Department of Family Studies, and myself. My thesis committee, namely Dr. Nancy Higgitt, Dr. John Bond and Dr. David Gregory, will only have access to the coded transcripts. No one reading the results will be able to identify you. The information that you share with me along with other resources will be used to complete my thesis research. The study may be submitted for publication in an academic journal.

I hope that you will participate in this study. Please feel free to call me at # or my thesis advisor, Dr. Nancy Higgitt, Department of Family Studies, University of Manitoba at # if you have any questions. If you would be willing to participate in this study, please contact Réjeanne Bérard, social worker at Foyer Valade. Please give her your phone number so that I may contact you to arrange a convenient time for us to meet. Thank you for your consideration.

Micheline St-Hilaire

Monsieur, Madame,

Je m'appelle Micheline St-Hilaire et je suis candidate à la maîtrise au *Department of Family Studies* de l'Université du Manitoba. J'effectuerai une recherche au cours de l'été et de l'automne 1999 portant sur l'expérience des membres des familles franco-manitobaines qui visitent un membre de leur famille dans un établissement de soins de longue durée.

#### **Description de la recherche**

J'effectuerai cette étude au moyen d'entrevues et d'observations. Il me faut donc trouver des personnes apparentées, par alliance ou par le sang, à un résident ou à une résidente pouvant donner son consentement, qui se disent Franco-Manitobaines, et qui ont l'habitude de venir passer du temps avec ce résident ou cette résidente. Votre participation pourrait contribuer à une meilleure compréhension de ce type de visite par les professionnels, les visiteurs et les résidents de ce genre d'établissement. Veuillez noter que le Foyer Valade, ainsi que le *Faculty of Human Ecology Ethics Review Committee* de l'Université du Manitoba ont consenti à ce que j'effectue cette recherche.

#### **Procédure**

Je vous prie de m'aider dans ma recherche en acceptant de répondre à certaines questions, afin que je puisse apprendre davantage sur la nature des visites à une personne résidant dans un établissement de soins de longue durée. Si vous acceptez, je me rendrai à un endroit de votre choix, pour une entrevue d'une à deux heures. Les questions porteront sur ce qui se passe lors de vos visites au membre de votre famille en établissement. Avec votre permission, j'enregistrerai l'entrevue afin de faciliter l'analyse de l'information que vous fournirez. Je vous demanderai plus tard la permission d'observer une de vos visites avec votre membre de famille, afin de me renseigner davantage sur cette expérience. Vous aurez l'occasion de choisir si vous aimeriez que l'entrevue se passent en français ou en anglais.

#### **Participation volontaire**

Veuillez noter que vous êtes tout à fait libre de participer ou non, et que votre choix n'aura aucune conséquence sur les soins prodigués, maintenant ou plus tard, au membre de votre famille actuellement en établissement. Vous pouvez mettre fin à l'entrevue en tout temps et choisir de ne pas répondre à l'une ou l'autre des questions, demander d'arrêter l'enregistrement, ou vous retirer, en tout temps.

#### **Confidentialité**

En aucun cas je ne révélerai votre identité, sauf à ma conseillère de thèse, M<sup>me</sup> Nancy Higgitt du *Department of Family Studies* de l'Université du Manitoba. Les membres du jury qui évalueront ma thèse, c'est-à-dire M<sup>me</sup> Nancy Higgitt, M. John Bond et M. David Gregory, n'auront accès qu'à la transcription des entrevues. Aucun lecteur de ce document ne sera en mesure de vous identifier. Les renseignements ainsi obtenus serviront, en conjonction avec d'autres ressources, à compléter ma thèse de maîtrise. Il se pourrait que les résultats soient publiés dans une revue spécialisée.

Je souhaite que vous acceptiez de participer à cette recherche. Pour de plus amples renseignements, n'hésitez pas à communiquer avec moi au #, ou avec ma conseillère de thèse, M<sup>me</sup> Nancy Higgitt du *Department of Family Studies* de l'Université du Manitoba au #.

Si vous acceptez de participer à la recherche, veuillez communiquer avec Réjeanne Bérard, travailleuse sociale au Foyer Valade. S'il vous plaît lui donner votre numéro de téléphone afin que je puisse vous rejoindre pour prendre rendez-vous. En vous remerciant pour l'attention que vous porterez à ma demande, je vous prie d'agréer, Monsieur, Madame, l'expression de mes sentiments distingués.

Micheline St-Hilaire

## Appendix E

Interview GuideDemographic Questions**VISITOR**Gender: Male  Female 

Age: \_\_\_\_\_

Level of education: \_\_\_\_\_

Employment status: \_\_\_\_\_

Household composition: \_\_\_\_\_

Marital status: Single  Married  Widowed  Separated/Divorced Other \_\_\_\_\_ 

Relationship to resident: \_\_\_\_\_

How many children in your family : \_\_\_\_\_

Residential propinquity: \_\_\_\_\_

Frequency of visits over the past 6 months: \_\_\_\_\_

Length of visits over the past 6 months: \_\_\_\_\_

What time of day do you visit?: \_\_\_\_\_

Who comes with you when you visit? : \_\_\_\_\_

**RESIDENT**Gender: Male  Female 

Age: \_\_\_\_\_

Marital status: Single  Married  Widowed  Separated/Divorced Other \_\_\_\_\_ 

Length of time in long-term care: \_\_\_\_\_

Where did your relative live before they moved here? : \_\_\_\_\_



### Descriptive Questions

Descriptive questions or “grand tour” questions give the interviewer a general view of the informant’s perspective. Such questions will include:

- Will you tell me about the time you spend with relative?
  - Tell me about the last time you saw relative.
  - What do you do when you spend time with relative?
- What is it like to have a relative in long-term care?
- Tell me about how you feel when you visit? after you visit?
- Do you discuss your visits with anyone?

### Structural Questions

Structural questions provide more specific information and are frequently asked concurrently with the descriptive questions. They serve to tell the interviewer how informants organize their cultural knowledge (Sorrell & Redmond, 1995). Examples of topics that will be covered include:

- Will you tell me the kinds of activities you do when you spend time with relative?

The following Family Involvement Inventory developed by (Linsk et al., 1988) outlines the areas to probe:

- Activities of daily living (e.g. feeding, manicuring, pedicuring, shaving, bathing, setting hair, hair cutting, toileting)
- Exercises (e.g. passive range of motion, help turning resident in bed, encourage resident to propel wheelchair, walking outside, walking in hallways)
- Visiting (e.g. visit \_\_ times per \_\_wk\_\_mo\_\_yr, play board games, drawing, play cards, bring favorite snack, bring lotion for massage, give back or body massage, bring flowers, bring perfume, bring family pictures, bring framed pictures, bring grandchildren or other children, discuss family activities, help make telephone calls, discuss daily situations, discuss important family matters)
- Reality orientation (e.g. tell relative who you are during each visit, talk about day, month, year, refer to past and present shared activities, remind resident of where he/she is living, talk about roommates by name, make newspaper available, make books, magazines available, talk about weather, season, discuss current events)
- On Floor Activities (e.g. conduct activity, help with activities regularly, sponsor special event, assist residents in activity, participate in scheduled activities)
- Home Wide Activities (e.g. help transport relative to activities in the home, take relative off floor for soda, coffee)

- Other activities (e.g. help transport relative to activities in home, take out to restaurant, take to doctor, ensure drugs are ordered, provide supplies (e.g. tissues, creams), help keep room attractive, report abuse to home and authorities, launder clothes, inventory clothes, repair clothing, file benefit claim, give resident birthday party)
- What are your conversations like?
  - How do you greet each other/how do you prepare to leave each other?
  - What do you talk about?
  - Who does the most talking?
  - What difficulties, if any, arise during your conversations?
- What was your relationship like with your relative before institutionalization?
  - What aspects of your relationship have changed/stayed the same?
  - What type of activities did you share with your relative before institutionalization?
  - What kind of relationship do you have now with your family member?
- Will you tell me what you find satisfying about spending time with relative?
  - What is the most enjoyable part?
  - What is the most satisfying part?
  - How does the time you spend impact the life of relative?
  - How does the time you spend with relative impact the institution as a whole?
- Will you tell me what you find challenging when you spend time with relative?
  - What is the most difficult part?
  - Do you have any problems in particular you feel should be addressed?
  - What challenges are specifically related to your relative?
  - What challenges are specifically related to the institution or the staff?
- Do you have contact with people other than your relative in the institution?
  - Who do you have contact with?
  - What type of relationship do you have with these people?
  - What kinds of things do you do with these people?
  - What do these other relationships provide to you?
- How do you maintain cultural and personal continuity for your family member in a Franco-Manitoban long-term care setting?
  - What kinds of things do you do to maintain your culture?
  - Which language do you and relative speak when you spend time together?
  - If you share stories, what types of stories do you tell?
  - If you sing, what types of songs do you sing?

- When you bring food, what type of foods do you bring?
- Is religion part of your visit? If so, how do you practice your faith with relative?

### Contrast Questions

Contrast questions help the interviewer discover the meanings of words that informants use to describe their culture, by finding similarities and differences in how they see the words (Sorrell & Redmond, 1995). Such questions include:

- If you had to write a job description for what you do, what would it say?
- You used the term “caregiver” and the term “visitor”, what is the difference between the two terms?

## Guide d'entrevue

## Questions démographiques

**PERSONNE VISITEUSE**Sexe : masculin  féminin 

Âge : \_\_\_\_\_

Degré d'instruction : \_\_\_\_\_

Emploi : \_\_\_\_\_

Composition du ménage : \_\_\_\_\_

État civil : célibataire  mariée  veuve  séparée ou divorcée  autre 

Lien de parenté avec le résident ou la résidente : \_\_\_\_\_

Combien d'enfants êtes-vous dans votre famille : \_\_\_\_\_

Proximité de l'établissement : \_\_\_\_\_

Fréquence des visites au cours des 6 derniers mois : \_\_\_\_\_

Longueur des visites au cours des 6 derniers mois : \_\_\_\_\_

A quel moment de la journée est-ce que vous visitez ? \_\_\_\_\_

Qui est-ce qui vient visiter avec vous ? \_\_\_\_\_

**RÉSIDENT OU RÉSIDENTE :**Sexe : masculin  féminin 

Âge : \_\_\_\_\_

État civil : célibataire  mariée  veuve  séparée ou divorcée  autre 

Réside dans un établissement depuis combien de temps ? \_\_\_\_\_

Où est-ce que votre parent vivait avant de déménager ici ? \_\_\_\_\_

### Questions descriptives

Les questions descriptives, ou le « grand tour » donnent une idée générale du point de vue de la personne interrogée. Ce sont des questions comme:

- Parlez-moi du temps que vous passez avec votre parent:
  - Quand l'avez-vous visité pour la dernière fois?
  - Que faites-vous lorsque vous êtes ensemble?
- Qu'est ce que ça vous fait d'avoir un parent dans un établissement de soins de longue durée?
- Dites-moi comment vous vous sentez lorsque vous lui rendez visite? Et après la visite?
- En parlez-vous avec quelqu'un d'autre?

### Questions structurelles

Les questions structurelles permettent d'obtenir des renseignements précis. On les pose en simultanéité avec les questions descriptives. Elles indiquent à la personne qui mène l'entrevue de quelle manière les répondants organisent leurs connaissances culturelles (Sorrell et Redmond, 1995). À titre d'exemples :

- Pourriez-vous me nommer des activités que vous faites avec votre parent lorsque vous passez du temps avec lui?

La liste ci-dessous, relative à la participation de la famille (Linsk et al., 1998), résume les domaines à explorer de façon particulière:

- activités de la vie quotidienne (alimentation, soins des ongles, soins des pieds, rasage, bain, coiffure et coupe des cheveux, toilette en général);
- exercice (amplitude des mouvements, positionnement dans le lit, fauteuil roulant, promenade à l'extérieur, marche dans le corridor);
- visite (visite \_\_ fois par sem. \_\_ mois \_\_ année \_\_, jeux de table, dessin, cartes, goûter préféré, lotion de massage, massage corporel ou dorsal, fleurs, parfum, photos de famille, cadres décoratifs, petits-enfants ou autres enfants, discussion sur les activités de la famille, appels téléphoniques, situations de la vie quotidienne, affaires importantes de la famille);
- orientation (dire qui on est, quel jour on est, quel mois, quelle année, parler des activités communes, passées et présentes, rappel du lieu de résidence passé, nommer les compagnons ou les compagnes de chambre, apporter des journaux, des livres ou des revues, parler de la température ou de la saison, parler de l'actualité);
- activités dans le service (animer l'activité, aider périodiquement à l'organisation d'activités, parrainer certaines activités, aider les résidents qui participent à l'activité, participer aux activités à l'horaire);
- activités de l'établissement (amener le résident ou la résidente sur les lieux de l'activité, sorties hors du service pour un café, etc.);
- autres activités (amener le résident ou la résidente à des activités à domicile, sortie au restaurant, rendez-vous chez le médecin, fourniture des médicaments, de mouchoirs de papiers, de crèmes, etc., décorations de la chambre, dénonciation de mauvais traitements, lessive, examen des vêtements, réparation des vêtements, remplir certains formulaires, fêtes d'anniversaire).

- De quoi parlez-vous?
  - Comment vous saluez-vous? Sur quelles paroles vous quittez-vous?
  - Qui parle le plus?
  - Quelles difficultés rencontrez-vous au cours de ces conversations?
- Est-ce que vous vous parlez au téléphone?
- Comment vous entendiez-vous avec votre parent avant que cette personne n'aille dans un établissement de soins de longue durée?
  - Qu'est-ce qui a changé? Qu'est-ce qui est resté comme avant?
  - À quel type d'activités vous êtes-vous adonné avec votre parent avant que cette personne n'aille dans un établissement de soins de longue durée?
  - Quel type de relation avez-vous à présent avec cette personne?
- Pouvez-vous me dire ce que vous trouvez de satisfaisant dans ces visites?
  - Qu'est-ce qui est le plus agréable?
  - Qu'est-ce qui est le plus satisfaisant?
  - Quel impact le temps que vous passez avec votre parent a-t-il sur sa vie?
  - Quel impact le temps que vous passez avec votre parent a-t-il sur l'établissement?
- Pouvez-vous me dire ce que vous trouvez le plus difficile dans ces visites?
  - Qu'est-ce qui est le plus difficile?
  - Y a-t-il un problème en particulier dont vous aimeriez parler à quelqu'un ou que vous aimeriez résoudre?
  - Quelles sont les difficultés plus particulièrement reliées à votre parent?
  - Lesquelles sont plus particulièrement reliées au personnel ou à l'établissement?
- Communiquez-vous avec d'autres personnes que votre parent dans l'établissement?
  - Si oui, avec qui?
  - Quel type de relation entretenez-vous avec ces personnes?
  - Que faites-vous avec ces personnes?
  - Que vous apportent ces relations?
- De quelle façon arrivez-vous à garder un lien culturel et personnel avec votre parent dans le contexte d'un établissement franco-manitobain?
  - Que faites-vous pour conserver votre culture?
  - Dans quelle langue vous exprimez-vous lorsque vous êtes avec votre parent?
  - Si vous racontez des histoires, celles-ci sont de quel type?
  - Si vous chantez, quel genre de chansons chantez-vous?
  - Si vous apportez des aliments, quels sont-ils?
  - Parlez-vous de religion? Si oui, de quelle manière s'exprime votre pratique religieuse avec votre parent?

#### Questions de contraste

- Si vous deviez rédiger une description d'emploi pour ce que vous faites, que diriez-vous?
- Vous avez employé les termes « pourvoyeur de soins » et « visiteur », quelle est la différence entre ces deux termes selon vous?

## Appendix F

### Script to Obtain Consent

#### **Description of study**

You are invited to participate in the study of visiting experiences of Franco-Manitoban family members who visit kin in long-term care. The facility as well as the Faculty of Human Ecology Ethics Review Committee of the University of Manitoba have given me permission to conduct this study.

#### **Procedures**

The interview with the visitor will last approximately one to two hours and will be tape recorded. I would also like to observe one of your visits with your family member in long-term care at a later date for the length of your visit or one to two hours. Some note may be taken during the observation.

#### **Benefits and risks**

There may be no direct benefits to participating in this study. However, it is possible that your participation may increase the understanding of the visiting experience for professionals in long-term care.

There are no known risks of participating in this study.

#### **Voluntary Participation**

Your participation in this study is entirely voluntary and will in no way affect the care that your family member is receiving, or the care that they will receive in the future whether you agree to participate or not. You also have the right to refuse to answer any questions, have the tape recorder turned off or withdraw from the study at any time.

#### **Confidentiality**

Your identity will remain confidential. Only my thesis advisor, Dr. Nancy Higgitt, and I will know your identity. To maintain your confidentiality, a code will be assigned and your name will not be used. Only Dr. Nancy Higgitt and I will have access to the list of participants and this list will be stored in a locked filing cabinet in a different location than the tape recorded interviews and the typed transcripts. My thesis committee, namely Dr. Nancy Higgitt, Dr. John Bond and Dr. David Gregory, will have access to the coded transcripts. The list of participants and any other information identifying the participants will be shredded and destroyed following completion of the thesis. The transcripts will be stored in a locked filing cabinet for a period of seven years and shredded and destroyed thereafter.

## Texte de questions à poser afin d'obtenir un consentement

### Description de la recherche

Je vous invite à participer à une recherche portant sur les visites effectuées par les Franco-Manitobains à un membre de leur famille qui réside dans un établissement de soins de longue durée. L'établissement, ainsi que le *Faculty of Human Ecology Ethics Review Committee* de l'Université du Manitoba ont consenti à ce que j'effectue cette recherche.

### Procédure

L'entrevue prend environ une à deux heures et est enregistrée. Plus tard, j'aimerais également observer l'une de vos visites à votre parent pendant une à deux heures. Je prendrai des notes durant ce temps.

### Avantages et risques

Vous ne retirerez probablement aucun avantage direct à participer à cette recherche. Toutefois, vous pourriez ainsi contribuer à une meilleure compréhension de ce type de visite par les professionnels de ce genre d'établissement.

Il n'y a aucun danger connu à participer à l'étude.

### Participation volontaire

Vous êtes tout à fait libre de participer ou non à cette recherche. Votre choix de participer ou non n'aura aucune conséquence sur les soins prodigués à votre parent, maintenant ou plus tard. Vous avez le droit de refuser de répondre à l'une ou l'autre des questions, demander d'arrêter l'enregistrement, ou vous retirer, en tout temps.

### Confidentialité

Votre identité ne sera pas dévoilée. Seule ma conseillère de thèse, M<sup>me</sup> Nancy Higgitt, et moi-même connaissons votre nom. Nous attribuerons un code à votre nom et celui-ci ne sera jamais utilisé. Seuls le docteur Higgitt et moi-même aurons accès à la liste des participants et cette liste sera mise sous clé dans un endroit différent de celui où les bandes enregistrées et les transcriptions seront rangées. Mon jury de thèse, soit M<sup>me</sup> Nancy Higgitt, M. John Bond et M. David Gregory, n'aura accès qu'aux transcriptions. La liste des participants, et tout autre renseignement qui pourraient permettre de les identifier, seront déchetés et détruits dès que la thèse sera terminée. Les transcriptions seront mises sous clé pendant une période de sept ans, puis déchetées et détruites.



## Appendix G

Consent Form

**Project Title:** Visiting: Experiences of Franco-Manitobans who visit family members in long-term care

**Principal Investigator Name:** Micheline St-Hilaire

**Tel:** 1 (204) #

**Address:** Winnipeg, Manitoba

**Names of co-investigators:**

1. Dr. Nancy Higgitt: 1 (204) #

2. Dr. John Bond: 1 (204) #

3. Dr. David Gregory: 1 (204) #

**PLEASE TICK EITHER YES OR NO IN RESPONSE TO EACH OF THE FOLLOWING QUESTIONS:**

- |    |  |     |                       |    |                       |
|----|--|-----|-----------------------|----|-----------------------|
| 1. | Do you understand that you have been asked to be in a research study?  | Yes | <input type="radio"/> | No | <input type="radio"/> |
| 2. | Have you read the information sheet or heard the verbal explanation of the investigator?   | Yes | <input type="radio"/> | No | <input type="radio"/> |
| 3. | Do you understand the benefits and risks involved in taking part in the research study?  | Yes | <input type="radio"/> | No | <input type="radio"/> |
| 4. | Have you had an opportunity to ask questions and discuss the study?  | Yes | <input type="radio"/> | No | <input type="radio"/> |
| 5. | Do you understand that you are free to withdraw from the study at any time without having to give a reason and without any detriment to the care that your family member is receiving or the care that they will receive in the future in the institution? | Yes | <input type="radio"/> | No | <input type="radio"/> |
| 6. | Do you understand that you can refuse to answer any questions or withdraw from the study at any time?  | Yes | <input type="radio"/> | No | <input type="radio"/> |
| 7. | Has the issue of confidentiality been described to you and do you understand: a) who will have access to the information you provide, b) that no reports will identify you as an individual?   | Yes | <input type="radio"/> | No | <input type="radio"/> |

I agree to take part in this study      Yes         No  

\_\_\_\_\_  
Signature of family member

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of resident

\_\_\_\_\_  
Date

Two copies of this form are provided for you to complete, one of which you are expected to keep. The second copy will be kept by the principal investigator. Thank you.

\_\_\_\_\_  
Signature of researcher

\_\_\_\_\_  
Date

## Formulaire de consentement

**Titre du projet:** Visites : expériences vécues par les Franco-Manitobains qui rendent visite aux membres de leur famille dans les établissements de soins de longue durée.

**Les entrevues et les observations seront principalement menées par :**

Micheline St-Hilaire                      Téléphone : 1 (204) #

**Adresse :** Winnipeg (Manitoba)

**Nom des autres personnes concernées :**

1. M<sup>me</sup> Nancy Higgitt : 1 (204) #

2. M. John Bond : 1 (204) #

3. M. David Gregory : 1 (204) #

**VEUILLEZ COCHER OUI OU NON SELON LE CAS :**

- |   |     |                       |     |                       |
|---|-----|-----------------------|-----|-----------------------|
| 1. Comprenez-vous qu'on vous demande de participer à une recherche?   | Oui | <input type="radio"/> | Non | <input type="radio"/> |
| 2. Avez-vous lu la feuille de renseignements ou entendu les explications données oralement par la personne qui mènera l'entrevue?   | Oui | <input type="radio"/> | Non | <input type="radio"/> |
| 3. Comprenez-vous les avantages et les risques reliés à la participation de cette recherche?  | Oui | <input type="radio"/> | Non | <input type="radio"/> |
| 4. Avez-vous eu la possibilité de poser des questions et de parler de la recherche?   | Oui | <input type="radio"/> | Non | <input type="radio"/> |
| 5. Comprenez-vous que vous avez la possibilité de vous retirer en tout temps, sans avoir à vous justifier, et sans que les soins prodigués à votre parent dans l'établissement de soins de longue durée ne soient en rien modifiés, que ce soit à présent ou dans l'avenir? | Oui | <input type="radio"/> | Non | <input type="radio"/> |
| 6. Comprenez-vous que vous pouvez refuser de répondre à l'une ou l'autre des questions, ou vous retirer en tout temps?  | Oui | <input type="radio"/> | Non | <input type="radio"/> |
| 7. Vous a-t-on expliqué la notion de confidentialité? Comprenez-vous : a) qui aura accès aux renseignements que vous donnerez; b) qu'aucun rapport ne contiendra de renseignements permettant de vous identifier?   | Oui | <input type="radio"/> | Non | <input type="radio"/> |

\_\_\_\_\_  
 J'accepte de participer à cette recherche    Oui        Non   

\_\_\_\_\_  
 Signature du visiteur

\_\_\_\_\_  
 Date

\_\_\_\_\_  
 Signature du résident ou de la résidente

\_\_\_\_\_  
 Date

Vous recevrez deux exemplaires de ce formulaire. Remplissez les deux, conservez-en un. L'autre restera en possession de la personne responsable des entrevues. Merci.

\_\_\_\_\_  
 Signature de la responsable de la recherche

\_\_\_\_\_  
 Date

## Appendix H

Gestalt of the Interview**Interview #** \_\_\_\_\_**Date:** \_\_\_\_\_**Time in Field:** \_\_\_\_\_**Time for Field Notes:** \_\_\_\_\_**Preparation for the interview**

--

**General observations of the long-term care setting**

--

**Overall impression of the interview**

--

**Issues to be addressed in following interviews and observations**

--

## Appendix I

Observation Guide(based on Spradley, 1980)

Observation # \_\_\_\_\_

Date: \_\_\_\_\_

Time in Field: \_\_\_\_\_

Time for Field Notes: \_\_\_\_\_

<b>DIMENSIONS OF SOCIAL SITUATIONS</b>	
<b>Space (the physical place or places)</b>	
<b>Object (the physical things that are present)</b>	
<b>Act (single actions that people do)</b>	
<b>Activity (a set of related acts people do)</b>	
<b>Event (a set of related activities that people carry out)</b>	
<b>Time (the sequencing that takes place over time)</b>	
<b>Actor (the people involved)</b>	
<b>Goal (the things people are trying to accomplish)</b>	
<b>Feeling (the emotions felt and expressed)</b>	

**Issues to be addressed in following interviews and observations**

--

## Appendix J

Data reconstruction and synthesis products

Reference	e.Coding	Int.#	Pg #	Line #	Direct quote	Translation	Codes	Memos
		8201			that her mother doesn't kiss her back. <input type="checkbox"/> V proceeds to fix cucumbers, and com-on-the-cob from the garden. <input type="checkbox"/> When granddaughter arrives, she proc		Act	
		2011	6	286-294	Saut le samedi parce que je viens à la messe à quatre heures, ici, et puis là on chante ensemble. Je me mets près d'elle/on chante ensemble. Puis souvent je vais souper avec elle... Là je suis ici depuis trois heures, et on soupe ensemble et après ça ils lu	HUMAN TRAIL	Activities	SPIRITUAL CULTURE SHARING MEALS
		2211	7	298-299	...mais assez souvent je mange avec elle, mois souvent là mais au début...		Activities	Used to share meals in LTC selling more in the beginning I wonder why??
		7411	23	1099-1101	faillue pour jouer aux cartes, jamais. On a toujours fait ça.		Activities	always played cards therefore it continues R only likes card games she knows - V respects that.
		7511	24	1108-1109	Non. Mais elle n'aime pas apprendre un nouveau jeu.		Activities	TV; Reminiscing; Enjoyment
		11113	4	147-154	On a regardé la télévision ensemble, il y avait ma femme et mon frère, alors on parlait du passé, puis elle aime ça, elle aime bien ça. Et puis je pense qu'elle aime ça elle temps a passé vite, et puis elle aime ça. Alors le peu de temps qu'on peut		Activities	
		11713	5	197-208	On va descendre en bas avec, on va prendre un café, on va l'amener - souvent je vais venir la chercher pour prendre un café, et je dis à place de prendre un café ici, j'appelle mon frère et puis on s'en vient, on va aller prendre un café là, et je la roui		Activities	time to visit other family members also.
		12213	6	261-264	On la sort beaucoup. Je l'amène - on va l'amener souper, on va l'amener chez nous, on va aller visiter ses amis à leur maison.		Activities	
		13913	12	535-551	Faire des petites affaires avec elle, des grosses affaires avec elle. Je l'amène - ma fille chante beaucoup, alors on l'amène à ses concerts... et puis ensuite on a été soupé au restaurant.		Activities	includes grandchildren.
		12571-574	12	571-574	Elle sort plus aujourd'hui qu'elle a jamais sorti. Mais pour nous autres ça nous donne une activité à faire avec elle.		Activities	do. useful to have an activity to

IMPROVISE  
OF SHELTERS  
14113  
AGILITY  
THINGS TO DO

FAMILY  
OUTINGS

FAMILY

ACTIVITIES  
FAMILY CONTINUITY  
& TV.  
CONNECTIONS

LANGUAGE

ACTIVITIES  
CARDS

HEALTH

ACTIVITIES  
LEAPERS

ENGAGEMENT