
**ÉTUDES SUR LES SOINS OFFERTS À
DOMICILE ET EN MILIEU
COMMUNAUTAIRE RÉALISÉES DANS
UNE PERSPECTIVE SENSIBLE AUX
DIFFÉRENCES ENTRE LES SEXES :
DOCUMENT DE SYNTHÈSE**

R A P P O R T F I N A L

Rapport commandé par le Bureau pour la santé des femmes de Santé Canada et financé conjointement par l'Unité des soins à domicile et des soins continus de la Direction des soins de santé de Santé Canada et de la Condition féminine Canada

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Le contenu du présent document ne représente pas nécessairement l'opinion du Bureau pour la santé des femmes de Santé Canada ou celle du gouvernement du Canada.

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RÉSUMÉ

Objet

Le présent document de synthèse porte sur 45 études traitant des soins et du soutien à domicile et dans la communauté dans une perspective fondée sur l'égalité entre les hommes et les femmes. Cette synthèse a plusieurs objectifs :

- Effectuer une analyse critique des recherches réalisées principalement au Canada et traitant des soins et du soutien à domicile et dans la communauté dans une perspective fondée sur l'égalité entre les hommes et les femmes; et dresser une synthèse des constats formulés à propos des personnes qui prennent soin de leurs proches sans rémunération et des personnes qu'elles soutiennent. Autrement dit, les seules études considérées sont celles qui ont permis de recueillir des données sur le sexe des personnes souvent désignées comme aidantes « naturelles » et des bénéficiaires de ces soins (hommes et femmes, femmes seulement ou hommes seulement) et qui permettent de tirer des conclusions concernant les différences et les similitudes entre les hommes et les femmes et traitant de l'expérience spécifique vécue par les personnes de chaque sexe.
- Situer ces études dans le contexte de la restructuration des services de santé.
- Dégager, à partir de l'examen des recherches à caractère sexospécifique, les aspects qui n'ont pas été étudiés relativement aux services dispensés à domicile et dans la communauté.
- Déterminer les conséquences politiques des constats établis à propos des personnes, hommes et femmes, qui dispensent l'aide et les soins non rémunérés en accordant une attention toute particulière aux recommandations concernant les orientations politiques énoncées dans les études en question.
- Mettre en évidence la nécessité d'effectuer des analyses dans une perspective fondée sur l'égalité hommes-femmes dans le domaine des services à domicile ainsi que la pertinence de conduire des recherches sur la problématique hommes-femmes afin d'éclairer les choix politiques concernant les services à domicile et dans la communauté.

Constats de recherche et grands thèmes

La recherche axée sur la problématique hommes-femmes a notamment permis de faire les constats suivants :

- Les femmes forment la majorité des aidantes non rémunérées et des bénéficiaires de services. C'est pourquoi, elles sont particulièrement concernées par les politiques et les pratiques en matière de services à domicile.
- Les hommes et les femmes ne sont pas dans la même situation socioéconomique et ne sont pas confrontés aux mêmes attentes à cause des rôles différents assignés à chacun des sexes. Ainsi, les femmes consacrent plus d'heures que les hommes à prendre soin de leurs proches, sans rémunération; elles dispensent des soins beaucoup plus exigeants que ceux assurés par les hommes; elles parcourent de plus

grandes distances que les hommes pour fournir un tel soutien; elles offrent plus souvent que les hommes des soins et services non rémunérés; et elles doivent beaucoup plus souvent que ces derniers s'occuper de plus d'une personne ayant besoin de soutien.

Comme le fardeau qui pèse sur les femmes en matière de prestation de soins est beaucoup plus lourd, il n'est donc pas étonnant que, selon les recherches, l'aide et les soins aux proches aient un effet négatif plus important sur la santé des femmes que sur celle des hommes. Les femmes ont tendance à avoir des réseaux de soutien plus importants que les hommes, mais ces réseaux ne leur sont pas toujours utiles parce qu'ils sont aussi beaucoup plus souvent sources de conflits dans le cas des femmes que dans celui des hommes. La recherche montre également que l'aide et les soins perturbe davantage le quotidien et les plans d'avenir des femmes que ce n'est le cas pour les hommes.

Prendre soin d'un proche n'est pas une expérience négative pour toutes les femmes et tous les hommes. Divers facteurs contribuent au bien-être des personnes aidantes: les bonnes relations entre aidant et aidé; l'existence d'un réseau de soutien personnel; la reconnaissance, par la famille, du rôle joué par la personne aidante; les attentes réalistes et respectées par les professionnels de la santé quant au soutien demandé; le fait de donner un sens et de l'importance à l'expérience d'aide.

Toutefois, prendre soin d'un proche a un prix élevé au plan personnel et au plan financier, surtout dans le cas des femmes. Cette situation empiète davantage sur leur travail rémunéré des femmes comparativement aux hommes et bien qu'elle entraîne des coûts financiers pour les hommes et les femmes, ces dernières assument des coûts supérieurs à long terme.

Par ailleurs, il est possible que les attentes relatives aux rôles assignés à chacun des sexes expliquent une partie des résultats empiriques indiquant que les femmes bénéficient de moins d'heures de services que les hommes, quelle que soit leur situation : soins à long terme à cause de limitations fonctionnelles ou chroniques, ou à court terme, à la suite d'une opération. Les auteurs ont émis une théorie à cet égard : quand les professionnels font une évaluation des besoins afin de déterminer les soins à leur dispenser, on prend souvent pour acquis que les femmes sont plus en mesure que les hommes d'effectuer des tâches ménagères et de s'occuper de leurs soins personnels — même si elles souffrent de limitations fonctionnelles — parce que ces tâches font partie des rôles habituels attribués au sexe féminin.

Certains groupes sont confrontés à des problèmes particuliers et éprouvent plus de difficultés que d'autres : 96 p. 100 des personnes qui sont les principales responsables des soins aux enfants atteints d'incapacité sont des femmes; elles souffrent énormément des services inadéquats et du temps et des efforts incroyables qu'elles doivent consacrer à prendre soin de leurs enfants et à coordonner des services souvent décousus.

Chez les immigrants, les réfugiés et les minorités visibles, les personnes aidantes et aidées se heurtent au racisme ainsi qu'aux barrières linguistiques et culturelles. Les femmes autochtones qui dispensent ou qui reçoivent des soins sont plus désavantagées et moins bien servies que celles des autres groupes ethnoculturels. Les lesbiennes et les gais qui prennent soin de leurs proches se heurtent à des barrières et à un stress additionnels

quand ils s'occupent de leurs amis ou de leurs partenaires. De plus, quand ils tentent d'avoir accès à des services, il leur arrive de se heurter à l'hostilité et à la discrimination des dispensateurs de soins. Les femmes aidantes en milieu rural doivent assumer un fardeau supérieur à celui de leurs consœurs en milieu urbain et des hommes en milieu rural : les femmes aidantes en région rurale fournissent plus d'heures de soins non rémunérées que leurs consœurs des villes et que leurs homologues masculins de la campagne. De plus, les réseaux de soutien sont moins nombreux pour venir en aide aux femmes aidantes en milieu rural.

Il arrive que les femmes et les hommes qui reçoivent des services, soient victimes de violences et soient exposés à des risques pour leur sécurité physique, mais ce sont les femmes aidantes qui courent plus de risques que les hommes.

Nombre d'études réalisées dans différentes parties du pays parviennent à la même conclusion : la restructuration des services de santé — caractérisée par une réduction de la durée des séjours à l'hôpital, par la désinstitutionnalisation et par le déplacement des services vers le milieu de vie naturel — a été lourde de conséquence pour les femmes, surtout parce qu'elles doivent maintenant offrir davantage d'aide et de soins non rémunérés que ce qu'on attendait d'elles auparavant. En outre, la majorité des bénéficiaires de soins sont des femmes, dont la plupart vivent sous le seuil de la pauvreté et ne peuvent se payer des services privés quand les services publics sont inadéquats.

Certaines études ont soulevé la question de la participation civique: les personnes aidantes, qui sont principalement des femmes, et les personnes aidées qui sont essentiellement des femmes âgées et des femmes handicapées, sont ignorées dans le processus de décision sur les enjeux politiques les concernant. Les regroupements qui représentent les personnes retraitées, les personnes handicapées ou les personnes concernées par les services à domicile n'ont pas forcément recours à des analyses fondées sur l'égalité hommes-femmes dans leurs publications ou dans leurs représentations auprès du gouvernement.

Aspects non couverts par la recherche

Le présent document fait ressortir deux grandes lacunes dans la recherche :

- Des lacunes documentaires concernant les services à domicile et dans la communauté pour ce qui est de la recherche et de l'analyse fondées sur l'égalité hommes-femmes.
- Des aspects de la recherche qui ne sont pas couverts dans les écrits traitant de la problématique hommes-femmes dans le domaine des services à domicile.

Les recherches bibliographiques réalisées dans le cadre de la présente étude ont permis de constater que, sur plus de 2 000 études recensées dans le domaine des services à domicile et des soins de santé, 184 seulement tiennent compte de la problématique hommes-femmes.

Voici les principaux aspects qui ne sont pas couverts dans les écrits traitant de la problématique hommes-femmes dans le domaine des services à domicile :

- Données sur les hommes et les femmes autochtones et sur les services à domicile chez les Premières nations.
- Documentation canadienne axée sur la problématique hommes-femmes dans le domaine des services à domicile, dans le cas des immigrants, des réfugiés et des minorités visibles.
- Données statistiques concernant les lesbiennes, les gais et les personnes bisexuelles qui offrent ou reçoivent du soutien ou des soins.
- Recherches portant sur l'ensemble des personnes atteintes de limitations fonctionnelles et pas uniquement les personnes âgées ou les personnes handicapées de moins de 65 ans.
- Données sur les hommes et les femmes qui donnent des soins ou qui en reçoivent dans le contexte de limitations fonctionnelles de courte durée : patients en convalescence à domicile après une opération ou femmes venant d'accoucher et récupérant chez elles après avoir reçu un congé précoce de l'hôpital.
- Recherches examinant la situation des personnes aidantes qui ont aussi besoin de soins pour elles-mêmes, par exemple les femmes de plus de 65 ans qui s'occupent de leurs conjoints ou d'enfants adultes atteints d'incapacité ou femmes handicapées qui peuvent s'occuper de leurs enfants mais qui ont besoin de soutien parce qu'elles souffrent de limitations fonctionnelles.
- Données quantitatives complètes portant sur les répercussions financières moyennes au cours de la vie entière, (pour les femmes et les hommes) découlant de l'absentéisme, du nombre réduit d'heures de travail, des congés sans solde, des occasions d'apprentissage ratées et de tous les autres coûts cachés qui découlent du rôle de personne aidante. Des études montrent que ces répercussions sont principalement le lot des femmes aidantes.
- Recherches sur les options possibles en matière de programmes d'indemnité financière directe pour les personnes aidantes, incluant notamment une analyse actualisée comparant la situation au Canada et celle des autres pays industrialisés relativement aux services à domicile et aux mécanismes de soutien des personnes aidantes.
- Recherches qui ne se limitent pas à la formulation de recommandations à court terme destinées à aider les femmes à assumer leur rôle d'aidantes, mais qui visent à formuler des recommandations à long terme sur la façon de remettre en question le point de vue sexiste sur les attentes liées au rôle d'aidante.
- Recherche visant à déterminer la différence qui existe, pour la santé des personnes aidantes, entre le fait de dispenser des soins par choix et le fait d'y être contraint à cause de l'absence de solutions de remplacement.
- Recherche sur les hommes assumant le rôle d'aidant qui incombe traditionnellement aux femmes, notamment pour ce qui est des différences entre les quelques hommes qui fournissent un grand nombre d'heures de soins et la masse des hommes qui ne fournissent que quelques heures, afin de déterminer comment mieux répartir, entre les sexes, la responsabilité de l'aide et du soutien aux proches.
- Données régionales portant sur la problématique hommes-femmes en Alberta, à l'Île-du-Prince-Édouard, au Yukon, dans les Territoires du Nord-Ouest ou au Nunavut.

- Recherche destinée à établir des liens entre les différentes formes d'aide et de soins : rémunérés ou gratuits (lesquels sont essentiellement dispensés par les femmes), soins aux enfants et aux personnes atteintes de limitations fonctionnelles.
- Recherche servant à élaborer des stratégies destinées à appliquer les recommandations d'orientations fondées sur des données probantes afin d'améliorer les soins et le soutien offerts à domicile.

Répercussions et recommandations sur le plan politique

Dans les écrits portant sur l'aide et des soins à domicile, dans une perspective fondée sur l'égalité entre les hommes et les femmes, nous avons recensé plusieurs options de politiques. Certaines d'entre elles visent à améliorer les services, d'autres traitent des changements politiques plus importants pour revaloriser le rôle des personnes aidantes et l'expérience des personnes aidées. D'autres, enfin, concernent des changements politiques d'envergure destinés à s'attaquer aux causes profondes de l'inégalité entre les sexes dans le domaine des services à domicile. Ces recommandations ne concernent pas toute la problématique hommes-femmes, mais elles ont été élaborées à partir de recherches menées dans une perspective d'égalité hommes-femmes et d'une prise en compte des besoins particuliers des hommes et des femmes. Comme la plupart de ces recommandations visent à bâtir de meilleurs systèmes de soins et services à domicile et à alléger le fardeau des personnes aidantes, elles auront forcément une incidence plus grande dans le cas des femmes qui forment la majorité des aidantes et des aidées. Cependant, ces recommandations bénéficieront aussi aux hommes qui prennent soin de leurs proches, assumant ainsi un rôle traditionnel féminin, et à ceux qui se retrouvent dans une situation économique semblable à celle de la plupart des femmes atteintes de limitations fonctionnelles.

Voici quelques-unes des recommandations que l'on retrouve le plus souvent dans les écrits étudiés :

Amélioration de l'accessibilité

- Assurer un financement adéquat des services à domicile, des réseaux de soutien dans la communauté et des services institutionnels.
- Éliminer les frais de services de santé et de services de soutien qui occasionnent un transfert des coûts vers les dépenses privées des personnes. Ces frais limitent l'accès aux soins, à l'équipement et au soutien nécessaire pour un bon nombre de femmes, qui forment la majorité des personnes à faible revenu.
- Verser des indemnités de déplacement ou fournir une aide au transport pour les personnes aidantes et les bénéficiaires.
- Offrir des services de répit appropriés, au moment pertinent et à bas prix.
- Inclure dans les services gratuits et disponibles, des services - conseils à l'intention des personnes aidantes et des bénéficiaires.

- Mettre en place des politiques en milieu de travail qui tiennent compte des responsabilités en matière de soutien et de soin aux proches.

Amélioration de la qualité

- Offrir une formation dans le domaine des soins à domicile, aux travailleurs rémunérés et aux personnes aidantes non rémunérées.
- Sensibiliser les professionnels et les non professionnels qui sont en contact avec des personnes souffrant d'incapacités, aux besoins particuliers de ces personnes.
- Favoriser l'habilitation des bénéficiaires par la mise en place d'un mécanisme de plaintes transparent et confidentiel, permettant de prendre en compte leurs griefs et de faire enquête, sans qu'ils risquent d'en subir de conséquences négatives sur les soins qu'ils reçoivent.
- Élaborer des normes de qualité en matière de services à domicile, lorsqu'elles n'existent pas déjà, et évaluer les programmes de services à domicile pour s'assurer que ces normes sont respectées et que les bénéficiaires obtiennent les soins dont ils ont besoin sur les plans qualitatif et quantitatif.

Promotion de l'équité

- Analyser et corriger, s'il y a lieu, les processus d'évaluation en vue d'éliminer le sexisme dans l'estimé du nombre d'heures de services à domicile requis.
- Collaborer avec les milieux d'immigrants, de réfugiés et avec les minorités visibles afin de mettre sur pied des services culturellement appropriés.
- Collaborer avec les Premières nations, les Inuits et les Métis afin de mettre sur pied des services à domicile qui sont de qualité, adaptés à leurs réalités culturelles et accessibles aux populations autochtones dans toutes leurs collectivités, notamment au cœur des villes.
- Adopter une loi canadienne sur les services à domicile et dans la communauté, conformément à l'engagement du gouvernement fédéral d'appliquer des analyses fondées sur l'égalité hommes-femmes dans ses futures politiques et législations. Cette législation doit s'appuyer sur les principes de la *Loi canadienne sur la santé* (accessibilité, transférabilité, universalité, intégralité et administration publique), garantir l'accès à des services coordonnés, adaptés aux besoins, culturellement appropriés et publiquement imputables.
- Analyser les services offerts en vue d'en garantir la disponibilité, l'accessibilité, la souplesse, ainsi que l'adéquation aux besoins des personnes aidantes et des bénéficiaires.
- Appuyer la création de groupes et d'organisations de soutien conscients des écarts hommes-femmes en vue de représenter les intérêts des personnes aidantes et de leur fournir un soutien ainsi que des informations.
- Indemniser les personnes aidantes pour l'aide et le soutien à leurs proches sous la forme de congés fiscaux, de prestations de retraite, d'un salaire ou d'autres formes de dédommagements financiers.
- Analyser les programmes de sécurité du revenu, de soutien financier des personnes handicapées ainsi que les programmes fiscaux destinés à alléger la pauvreté.

Amélioration du processus de formulation des politiques

- Faciliter la participation des personnes aidantes et des bénéficiaires à la prise de décisions aux échelons local, provincial et fédéral.
- Analyser des programmes destinés aux personnes aidantes dans d'autres pays afin d'en dériver des modèles appropriés.
- Appliquer les questions suivantes à l'examen de toutes les politiques, lois et règlements :
 - Les personnes aidantes et les personnes aidées ont-elles donné un consentement éclairé?
 - Le soutien aux proches pourrait-il être également réparti entre les hommes et les femmes?
 - Les services peuvent-ils tenir compte des différences culturelles sans risquer de formuler des hypothèses indues au sujet des communautés culturelles, ni d'aller à l'encontre des autres principes en matière d'équité?
 - Les hypothèses sur les relations personnelles impliquées dans le soutien aux proches sont-elles fondées?
 - Peut-on tenir compte des différents intérêts à concilier dans le domaine du soutien aux proches?
 - Les besoins sont-ils définis de telle manière qu'on exclut certains groupes tandis qu'on en privilégie ou qu'on en stigmatise d'autres?
 - Quelles sont les conséquences à long terme?
 - Les objectifs visés sont-ils consolidés ou, au contraire, fragilisés par d'autres lois, règlements ou politiques?
 - Reconnaît-on la contribution et les compétences des personnes aidantes dans le soutien à leurs proches?
 - Les modes actuels de prestation de services découlent-ils d'orientations politiques ou bien les politiques traduisent-elles les préférences et les pratiques en cours?

Analyses fondées sur l'égalité hommes-femmes

Les analyses fondées sur l'égalité hommes-femmes ont pour but de favoriser la formulation de politiques favorables à la santé et s'appuyant sur des données probantes et sur une vision globale des façons dont les hommes et les femmes sont touchés par les mesures adoptées. Il est important que les politiques en question atteignent les résultats visés pour les hommes et les femmes et qu'elles contribuent à réduire les inégalités.

Pour aller dans le sens de l'engagement national et international du gouvernement du Canada à l'effet d'appliquer des analyses fondées sur l'égalité hommes-femmes à ses futurs programmes, politiques et lois, et pour aller dans le sens de l'engagement de Santé Canada d'appliquer systématiquement ces mêmes orientations dans tout le travail qui lui incombe, il faudra s'appuyer sur des données probantes en regard de la problématique hommes-femmes. Ce faisant, il sera possible d'élaborer des politiques équitables pour les hommes et pour les femmes.

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1. INTRODUCTION

The past two decades have seen an explosion in research about home and community care. Much of that work, however, fails to collect gender-sensitive data and analyze how programs and policies differently affect women and men. More than two-thirds of home care recipients are women, and the vast majority of unpaid caregivers are women. Beyond these difference in the numbers of men and women caregivers, the experience of women and men care recipients and caregivers varies as a result of male-female differences in socioeconomic status, social roles, lifestyles, physiological and psychological factors, and responsibilities. The consequences of the shift to home and community care may be different for women and men in areas such as health, income, employment and benefits, violence in the home, relationships between the care recipient and the caregiver or other family members, occupational health and safety, stress, isolation, other mental health issues, and expectations of the level of care provided or received.

1.1 PURPOSE OF THE SYNTHESIS PAPER

This paper has several purposes:

- to critically review and synthesize gender-sensitive research on caregiving and home and community care primarily in Canada, focusing on unpaid caregivers and recipients of care only. This means that only studies that collect data on the sex of unpaid caregivers and recipients (women and men, women only, men only) and draw conclusions as to gender differences, similarities, or gender-specific experiences are included here.
- to place these studies in the context of health care restructuring
- to identify gaps in gender-sensitive research about home and community care
- to identify the policy implications of the findings about women and men care recipients and unpaid caregivers, with particular attention to the policy recommendations of these studies
- to raise awareness and understanding of the need for gender-based analysis in the area of home and community care, and the need for gender-sensitive research to inform policy-making in the area of home and community care

As more gender-sensitive research on home and community care is available than could be reviewed in this paper, the following priorities were used to rank the studies to be included. Preference was given to recent original research, Canadian studies, studies that contain a gender analysis as opposed to those that mention gender in passing, studies that are specific to home and community care rather than to health care in general, and studies that deal with the diversity of women and men. Diversity includes race or ethnicity, Aboriginal ancestry and status under the *Indian Act*, language, age, ability, sexual orientation, and geographic location (rural versus urban, region of Canada). This paper excludes the literature about paid caregiving, as this area is being researched by Human Resources Development Canada (HRDC).

1.2 GENDER-BASED ANALYSIS

In 1995, the Government of Canada made a national and international commitment to apply a gender-based analysis to all proposed policies, programs, and legislation, where appropriate.¹ In 1999, Health Canada published Health Canada's *Women's Health Strategy*, which committed the department to the systematic application of gender-based analysis in all its substantive work.

As home and community care and caregiving are very much affected by gender differences, it is important that research be gender sensitive. Gender-sensitive research is more than counting women and men; it often means consulting written materials and organizations that have done gender-sensitive research in the area as a starting point, asking the right questions of research subjects or study participants, being aware of how different socioeconomic positions might affect the lives of women and men and their relationship to the issue under study, and, as a part of the analysis, looking for sex or gender differences or similarities for every variable.

Gender based analysis (GBA) is an analytical tool. It uses sex and gender as an organizing principle or a way of conceptualizing information — as a way of looking at the world. It helps to bring forth and clarify the differences between women and men, the nature of their social relationships, and their different social realities, life expectations and economic circumstances. It identifies how these conditions affect women's and men's health status and their access to, and interaction with, the health care system.

GBA provides a framework for analysing and developing policies, programs and legislation, and for conducting research and data collection — a framework that recognizes that women and men are not all the same. The GBA framework should be overlaid with a diversity analysis that considers factors such as race, ethnicity, level of ability and sexual orientation....

GBA performs the challenge function that is essential to sound policies and programs. It challenges the assumption that everyone is affected in the same way by policies, programs and legislation, or that health issues such as causes, effects and service delivery are unaffected by gender. It probes concepts, arguments and language used, and makes underlying assumptions and values transparent and explicit. Where these are revealed to be biased or discriminatory, GBA points the way to more equitable, inclusive options.

GBA is evidence-based. It is informed by data and knowledge gathered from research and through consultation with diverse groups of women and men.

Health Canada, *Health Canada's Gender-Based Analysis Policy*. (Ottawa: Health Canada, 2000), pp.1–2.

¹ This commitment was enshrined in Status of Women Canada, *Setting the Stage for the Next Century: The Federal Plan for Gender Equality* (Ottawa: Status of Women Canada, 1995), which was Canada's response to the *Platform for Action and the Beijing Declaration*, an international agreement signed at the United Nations Fourth World Conference on Women in 1995, to which Canada is a signatory.

The purpose of gender-based analysis is to develop good, evidence-based policy founded on a complete picture of how women and men are affected. It is important that policies result in expected outcomes for both women and men and reduce rather than exacerbate inequalities.

1.3 THE CONTEXT OF HOME AND COMMUNITY CARE RESEARCH AND POLICY

In Canada, as a result of a number of factors — including a trend toward independent living in the community, technological changes, health care cost pressures, changing demographics, and changing health care needs — there has been a shift from care in publicly funded institutions to care in private homes and the community. Acute, chronic, rehabilitative, and palliative care, as well as long-term supportive care for people with physical or mental disabilities or functional impairments, is now being provided in the home and community.

Provinces and territories are currently providing home care using different standards, eligibility requirements, administrative mechanisms, and costs to the user. Individuals who cannot get care or enough care to meet their needs through the public system are buying private home care. The federal government provides lump sum contributions to the provinces for health care, social services, and education through the Canada Health and Social Transfer (CHST). Provinces use these contributions, as well as provincial funds, at their discretion for health and education. At the present time, home care programs and services vary greatly across the provinces and territories. The federal government also provides a First Nations and Inuit Home and Community Care Program and a program administered through Veterans Affairs Canada.

Particularly between 1991 and 1996, the federal government and many provincial governments introduced fiscal restraint measures that affected health care and the people who rely on the public health care system. Since then, some governments have increased health care funding to some extent, but in some provinces health care funding freezes are still in effect. The Canadian Medical Association has been critical because, although more funds were recently injected into the health care system, they have not matched the needs of a growing and aging population.² Public and private health expenditures have risen dramatically over the years to \$95 billion in 2000,³ but the share of health care spending that is privately funded (by individuals and private insurance) has grown to 29% in 2000 from 24%, a rate that was relatively stable between 1975 and 1985.⁴ One of

² Canadian Medical Association, “Budget 2000: Health Care Funding Falls Short.” Media release. (Ottawa: CMA, February 28, 2000)

³ Canadian Institute for Health Information, “Total Health Care Spending to Top \$95 Billion, Reports Canadian Institute for Health Information.” Media release. (Ottawa: CIHI, December 11, 2000)

⁴ Canadian Institute for Health Information, “Total Health Expenditure by Source of Finance, Canada, 1975 to 2000 — Current Dollars.” Table A.2.2 National Health Expenditures Database (NHEX) (Ottawa: CIHI, last revised April 5, 2001) www.cihi.ca/facts/nhex/nhex2000/table_a.2.2.shtml

the most significant shifts is from reliance on hospital interventions to drug therapies, reflected in the fact that the growth in drug expenditures outpaces all other health care spending and in 2000 represented 15.5% of total health care spending, of which 33% was public sector spending.⁵ An analysis of health care system funding is well beyond the scope of this paper, but it is important to note that funding is an integral backdrop to, and perhaps even a driving force in, the progression toward home and community care.

Public home care expenditures have more than doubled in the last seven years, from \$1 billion in 1990–91 to over \$2 billion in 1997–98, an average annual rate of increase of almost 11.0%.⁶ As the studies in this paper and others reveal, this increase does not seem to keep pace with the needs of a growing and aging population, the trend toward earlier discharge from hospitals and fewer available hospital beds, the trend toward performing increasingly complex medical procedures in the home, and the more limited availability of mainly women family members to take on unpaid caregiving responsibilities. Home care also represents a privatization of costs, in terms of drugs (which would be free to the recipient in a hospital)⁷ and of labour, as the system relies in large part on the presumed existence of an unpaid labour force.

Policy interest in home care has increased over the past decade, but, by and large, gender implications and considerations have been marginal to policy discussions. The National Forum on Health recommended a national home care program in 1997. This was taken up as an election promise by the current government, culminating in a National Conference on Home Care in 1998 and a National Roundtable on Home Care in 1999. Organizations such as the Canadian Association of Retired Persons and the Canadian Home Care Association have been active on the issue of home care and have released studies and recommendations. None of these reports, however, discuss gender in any depth beyond a recognition that women form the majority of unpaid caregivers. Influential studies have been released, such as the Hospital and Home Care Study by the Health Services Utilization and Research Commission in Saskatchewan in 1998, which found that it costs the government \$830 more to provide a patient with non-acute care in hospital than at home, but no gender analysis was done to show who might be paying the price. Most recently, federal, provincial, and territorial Ministers of Health directed officials to develop a common vision and principles for home and community care, which the Ministers of Health forwarded to the First Ministers for consideration.⁸ Whether gender is

⁵ Canadian Institute for Health Information, “Spending on Drugs Outpaces Other Health Care Spending, Reports CIHI.” Media release. (Ottawa: CIHI, March 14, 2001)

⁶ Health Canada, “Public Home Care Expenditures in Canada, 1975–76 to 1997–98.” Fact sheet. (Ottawa, Health Canada, date unknown) www.hc-sc.gc.ca/datapcb/datahesa/E_home.htm

⁷ Coverage for prescription drugs for recipients of home care varies from province to province. Canadian Home Care Association, *Portrait of Canada: An Overview of Public Home Care Programs* (Ottawa: Health Canada, 1998)

⁸ Health Canada, “Health Ministers Move Forward on Improving Health Care in Canada.” News release. (Ottawa: Health Canada, September 26, 2001)

a factor in their report is unknown at this time, as the document has not been made public. The Commission on the Future of Health Care in Canada, chaired by the Hon. Roy Romanow, is currently in progress and due to report in the fall of 2002; this commission will no doubt also address home and community care, among other issues. Whether the commission is operating according to the federal government's gender-based analysis guidelines is unknown.

In summary, the discussion of home care policy takes place in a context that involves the increasing health care needs of the population, the limitations on the availability of traditional acute and chronic care facilities, the idea that community care is cost-effective for governments, and the existence of little or no gender-based analysis to determine the implications of home care policies for women and men.

1.4 TERMINOLOGY

In this paper, “informal caregiver” “family caregiver,” and “unpaid caregiver” are used interchangeably to refer to family members and friends who provide assistance to people with functional limitations, including adults of all ages and children with disabilities or chronic conditions, adults from age 18 to the end of life needing help with the activities of daily living, and people suffering from acute illness or patients in postoperative recovery. Generally, the term used matches that used in the study being reviewed. Debate about the use of particular terms occurs, however, both in English and in French, and should be noted.

“Informal caregiver” is sometimes seen as a misnomer because the formal system actually relies on the existence of “informal caregivers.” Although informal caregivers are not dispatched from any organization and their presence and duties are not guaranteed, without these caregivers, the formal system may well collapse. As well, some may view “informal caregiver” as a downplaying of the amount of work caregivers do, which may indeed exceed the work of a formal caregiver. “Family caregiver” does not necessarily capture all relationships between caregivers and care recipients, as some may not be blood relatives. “Family caregiver” also may suggest that the caregiving role is simply a natural part of family life, and therefore not of policy concern. “Unpaid caregiver” specifically calls attention to the fact that caregiving is work, and that the caregiver is not being paid for her or his work. “Aidant naturel” or “aidante naturelle” seems to imply that a person (usually a woman) is the natural helper of another person, and that unpaid caregiving is taken for granted as a woman performing her biologically driven role in life. “Aidant ou aidante en milieu naturel” means helper in the natural environment (the home) and may seem to some to imply a judgment about the best place to be cared for. “Personnes soignantes non rémunérées” both captures the caregiving role and calls attention to the fact that the work involved in it is unpaid. The terms used in the studies reviewed in this paper may well reflect the outlook of the authors on the caregiving role.

Home care can take many forms. Unpaid caregiving can include the following⁹:

- medical care: administering medication (by needle, mouth, or other means), helping with prescribed physiotherapy programs, changing colostomy bags, monitoring the recipient's medical condition, and calling for assistance when necessary. In the case of unpaid caregivers who have medical training, the medical duties may go beyond those mentioned here.
- personal care: assisting with bathing, dressing, walking, eating, getting in and out of a bed or chair, grooming, brushing teeth, cutting toenails, using the toilet, and changing incontinence garments
- housework: making the bed, doing laundry, preparing meals, cleaning up after meals, cleaning, washing floors, and vacuuming
- household maintenance: washing windows, putting up storm windows, painting, making repairs, mowing lawns, shoveling snow, and doing other yardwork
- errands: shopping, picking up prescriptions, providing transportation to and from medical and other appointments, and buying medical and other equipment
- financial management assistance: paying bills, filling in income tax returns, balancing chequebooks, and filling in applications for pensions and benefits
- emotional support: providing comfort, reassurance, and conversation; listening to the care recipient talk about problems; dealing with the care recipient's fears of illness and dying; and being a cheerful presence
- decision-making: having power of attorney, making daily decisions on behalf of the care recipient, and selling property
- monitoring: checking up on care recipients to ensure that their needs are met and the quality of services they receive is adequate. Sometimes supervision must be constant, as in the case of recipients who cannot be left alone.

Keating et al. (1999) posited that routine assistance becomes "care" when the assistance is compensating for functional loss. For example, concern and lending a helping hand become "care" when the individual's chronic health problem or disability necessitates that aid be given.

⁹ Most of this list is taken from Keating et al. (1999).

1.5 BRIEF OVERVIEW OF THE STUDIES REVIEWED

Some studies that included data from male and female research participants analyzed sex as a variable and reported gendered results. In some studies, all participants were male; other studies had only female participants. The vast majority of the gender-sensitive literature on home and community care and caregiving focused primarily on the gendered nature of caregiving rather than the gendered nature of receiving care. Some studies addressed both.

Some studies focused only on caregivers of seniors with functional limitations, on mainly adults under age 65 with disabilities or chronic illnesses, on children with disabilities, or on a combination of some or all of these. One study focused on care of people with acute illnesses and conditions, and a few studies included this group of care recipients as part of a larger whole. Gender-sensitive literature relevant to the care of such people is absent, probably because they constitute only a small minority of care recipients.

This synthesis paper examines caregiving and care receiving across the life span, excluding the care of children who do not have disabilities.¹⁰ The majority of gender-sensitive home and community care studies, however, looked only at the caregiving of seniors with functional limitations, a reality that is reflected in this synthesis paper.

The studies examined for this paper included literature reviews and studies based on empirical, qualitative, and participatory methodologies. Many were published in peer-reviewed journals. Some studies used a combination of quantitative methods supplemented by qualitative focus groups or interviews. As a whole, the studies examined for this paper — studies using different methods and combinations of methods — formed a relatively complete picture of certain aspects of gender and home and community care. There are, however, some gaps in this picture, particularly concerning gender and home care in marginalized populations. Research gaps are explored in Section 4.

2. METHOD

In a meeting with a Health Canada representative, relevant materials from federal and provincial government departments and the Centres of Excellence for Women's Health were identified. An extensive search for materials in both of Canada's official languages was undertaken, and representatives of community care organizations and academic experts were consulted.

¹⁰ Although caring for children without disabilities is certainly an important part of the caregiving equation for women, it is treated by governments and the research community as a separate issue.

The following sources were searched:

- the Internet
- bilingual holdings at the University of Ottawa/Université d'Ottawa
- Canadian Women's Health Network/Réseau canadienne pour la santé des femmes databases on Women's Health Resources and Women's Health Research/Projects
- MEDLINE (abstracts of 4,570 health journals worldwide)
- Social Work Abstracts
- PsychINFO (1,300 periodicals worldwide)
- Canadian Periodical Index (CPI-Q)
- Women's Resources International electronic database (includes Women's Studies Abstracts; Women's Studies Database; and New Books on Women, Women, Health and Development, and Women, Race, and Ethnicity)
- PAIS International database (public policy)
- Women's Health Matters/Femmes en santé, Sunnybrook and Women's College Health Sciences Centre website
- Canadian Health Network/Réseau canadien de la santé database
- Netfemmes online resources
- publications on the website of the B.C. Ministry of Children and Family Development, Community Living Services for Adults
- INDIE (Integrated Network of Disability Information & Education)
- DAIS, Health Canada's resource database, which includes unpublished reports

The online documentation of the following community organizations was searched:

- Réseau québécois d'action pour la santé des femmes
- L' Association féminine d'éducation et d'action sociale (AFÉAS)
- Caregiver Network
- Canadian Caregiver Coalition/La coalition canadienne des aidantes et aidants naturels
- Canadian Association of Independent Living Centres
- Canadian Association for Community Living
- Ontario Community Support Association
- Victorian Order of Nurses (VON)/Infirmières de l'Ordre de Victoria
- a number of associations to do with specific diseases, e.g., Canadian Cancer Society, Alzheimer Society

The following organizations were e-mailed a request for gender-sensitive home and community care materials:

- Canadian Home Care Association
- Aboriginal Nurses of Canada
- Pauktuutit Inuit Women's Association of Canada
- DisAbled Women's Network
- Council of Canadians with Disabilities
- Older Women's Network
- Women's Health in Women's Hands
- Riverdale Immigrant Women's Centre

The following experts in the area of women and caregiving were consulted:

- Carol Amaratunga, Maritime Centre of Excellence for Women's Health, who sent out the preliminary bibliography to her network to identify missing materials
- Pat Armstrong, York University
- Jane Aronson, McMaster University
- Denyse Côté, Université du Québec à Hull

Well over 2,000 recent studies about home and community care came to light, of which 184 were gender sensitive in some way. It was not possible to review all of these within the specified time frame and space limitations. The entries included in the bibliography of this paper (Section 6) were coded in terms of whether they reflect the following priorities: they contain a gender analysis specifically about home and community care and caregiving, are recent, are Canadian, and address diversity. With some exceptions, preference was given to reports of original research rather than to overviews of the research of others. Forty-five studies were reviewed for this paper.

It was not possible to review all the studies comprehensively. Many of them are filled with relevant data that deserve several pages of discussion. Priority was given to reporting data on gender differences or similarities; more general findings were left out.

The context of the data is extremely important to how they should be interpreted. Sample size, location of the study, methodological approach, and the interrelationship between the different findings within a single study are useful to know. These are reported in the first reference to a study.

Another decision about data presentation involved how to treat information about diversity — whether to integrate it into the main text or separate it by population group. The choice was made to separate it for the ease of researchers and policy-makers who are interested in the important questions of the experience of these populations: Aboriginal women and men; racial, ethnic, and linguistic minority women and men; lesbians and gay men; and rural women and men. If the little information available about these population groups were completely integrated into the text, it would be more difficult to find and attention would be diverted from these groups.

3. RESEARCH FINDINGS

3.1 WOMEN ARE THE MAJORITY OF UNPAID CAREGIVERS

The Statistics Canada 1996 General Social Survey (GSS) collected data from 12,756 people over age 15 in private households in all 10 provinces, but not the territories. These data enabled the construction of a statistical profile for most of Canada of those who give and receive care. The 1996 GSS analysis concentrated on eldercare. Sixty-one percent of caregivers of seniors with functional limitations were women (Keating et al. 1999).

Using the same data set, Cranswick (1997) pointed out that 10% of men versus 14% of women care for seniors with long-term health problems, and that caregivers are

concentrated in the 45 to 64 age group; 19% of women and 11% of men in this age group are caregivers to people with functional limitations.

Keating et al. (1999) noted that the 1996 GSS underestimates the number of caregivers, particularly women caregivers due to the following:

- Much caregiving of seniors is performed by women spouses of seniors, who might not view the work they have always done (meal preparation, laundry, etc.) as “care.”
- The statistics represent only who was caring for a senior at the time of the survey, and do not capture care over the lifetime, who has performed care in the past, and who will do so in future.
- The statistics do not include care for persons under age 65 with short- or long-term functional limitations.

Another important factor to consider is that statistics about the number of caregivers capture those who give assistance for amounts of time from a half-hour per week to 40 hours or more per week, those who check up once in a while on a person, and those involved daily in intimate personal care, such as changing incontinence garments.

3.2 WOMEN ARE THE MAJORITY OF CARE RECIPIENTS

Seniors with functional limitations are the largest user group of formal and informal home care, and the majority of seniors with functional limitations rely on some form of care in the home rather than resorting to institutionalization. According to the 1996 GSS, three-quarters of a million community-dwelling seniors received assistance because of long-term health problems, whereas data from the National Population Health Survey (NPHS) from 1995 show that 186,500 seniors lived in health care–related institutions (Keating et al. 1999: 23). According to Keating et al. (1999: 23), two-thirds (67%) of community-dwelling seniors receiving paid or unpaid care were women, and 73% of residents of health care–related institutions were women (Keating et al. 1999).

One of the reasons why women receive more home care could be because women have a longer life expectancy than men, and therefore make up the majority of Canada’s seniors. Another possible reason is that women play a caregiving role in the family, so that when the caregiver herself develops physical or mental limitations, the family seeks outside help. A third reason may be that since women tend to outlive their husbands, women are less likely than men to have a spouse to care for them in old age (Morris, Robinson, and Simpson 1999). Lower income people are also more likely to receive public home care services (Wilkins and Park 1998). The majority of low-income people in Canada are women (Statistics Canada 2000), making them more likely than men not to be able to afford private home care services (Morris, Robinson, and Simpson 1999).

For community-dwelling seniors who received care, 90% of assistance with household tasks and errands was provided by unpaid caregivers. Only 10% of help with these tasks was provided formally by government or non-government organizations or by a caregiver paid by the senior. Two-thirds of the personal, intimate care tasks were provided by family and friends (Keating et al. 1999).

Kaden and McDaniel (1990) looked at caregiving and care receiving using data from the 1982 Survey of the Elderly in the Waterloo region. The sample size was 403, about evenly matched between women and men, and stratified by the variables of age and rural or urban residence. These researchers found combined effects of age and gender: the older women had significantly lower income, had lived alone longer, had poorer health, and reported more loneliness than younger women and than older and younger men. Income level was unrelated to the use of formal home care services for men, but lower income was associated with the use of formal home care services for women.

3.3 WOMEN GIVE MORE HOURS OF CARE AND RECEIVE FEWER HOURS OF CARE THAN MEN

Although greater numbers of women than men receive assistance, women do not receive more hours of care. Female seniors with functional limitations received on average 3.9 hours of care per week, whereas men received 4.9 hours of care. Both female and male caregivers provided more hours of care to persons of the opposite sex; the difference was greater for female caregivers (who gave men recipients 6.9 hours of care and female recipients 4.3 hours) than for male caregivers (who gave female recipients 3.4 hours of care and male recipients 2.5 hours of care). As with the caregivers in general, the majority of caregivers of women are women (71.5%) (Keating et al. 1999).

Higher proportions of women seniors (30%) than men seniors (23%) received no assistance, which suggests that women are at greater risk of having their needs unmet (Keating et al. 1999).

Gender was also found to interact with marital status. Divorced and single women were more likely to receive assistance than married women, whereas the marital status of men did not affect their receiving assistance. This may be explained by differences in social networks. If husbands do not provide assistance to their wives, the wives may not have access to networks of other caregivers, whereas unmarried women, who have had to expand their social networks, may have such access (Keating et al. 1999).

For both men and women, the most significant predictor of care was health status, not age. The authors suggested that the assumption should not be made that an aging population will necessarily require more care, as long as the next cohort of seniors is in better health (Keating et al. 1999).

3.4 WOMEN RECEIVE LESS SHORT-TERM, POSTOPERATIVE HOME CARE THAN MEN

King and Koop (1999), medical researchers at the University of Alberta, pointed out that caregiving research has predominantly focused on caregivers of the elderly and of people with long-term illness. These researchers stated that little attention has been given to examining caregiving from the perspective of the person receiving the care. As well, even less research has been done on the influence of a person's sex or age on the care he or she receives, or on caregiving in the context of shorter term situations in which the patient is expected to recover. The authors followed 60 male and 60 female cardiac surgery patients from three Alberta hospitals, and their caregivers, and found that the patterns of informal caregiving noted in the chronic care literature are also present in the short-term care of postsurgical cardiac patients. The burden of caregiving continues to rest predominantly on women. Female patients relied on their spouses for help less frequently than did male patients, and the caregivers of female patients were more frequently employed outside the home and in lower status jobs than were the caregivers of male patients. Thirty percent of caregivers were reported to have a health problem of their own to manage while caring for the recovering patient. Patients who were male or who were under age 65 received more support than did patients who were female or who were 65 years old or older. The authors concluded that the cardiac patient's sex affects the availability of home-based care. In addition, caregivers may themselves be patients in need of care. The authors suggested that further research is necessary to examine the receipt of home-based caregiving, particularly for female patients.

3.5 FEMALE CAREGIVERS TEND TO BE OLDER THAN MALE CAREGIVERS

In a Canada-wide sample of 1,366 caregivers of seniors with functional limitations, the average age of the caregivers was 46 for women and 44 for men. Twenty percent of male caregivers were in their teens and twenties, compared with 13% of female caregivers. The highest number of hours spent caregiving was reported by women aged 60 to 74, and by men aged over 75 (Keating et al. 1999). Clearly, seniors should not be viewed solely as recipients or potential recipients of care, but also as caregivers.

The finding that the highest number of hours spent caring for seniors with functional limitations was provided by seniors (women aged 60–74 and men aged over 75) raises the issue of the vulnerability of older caregivers, who may be facing their own health problems (Keating et al. 1999).

3.6 CAREGIVERS' EMPLOYMENT, EDUCATIONAL, AND FAMILY STATUS AFFECT CAREGIVING

Fifteen percent of women with paid employment and 10% of their male counterparts were caregivers. Among the unemployed, 16% of women and 12% of men combined their job search activities with caregiving responsibilities. About 15% of women homemakers were caregivers of people with functional limitations. Sixteen percent of women living with a spouse and children were also caregivers of people with functional

limitations, compared with 14% of women living with a spouse but with no children at home (Cranswick 1997).

Thirty-eight percent of caregiving women were not in the paid labour force, compared with 22.2% of caregiving men. These women provided an average of 6.2 hours of care per week, compared with 5.0 hours for men. Having paid employment reduced the number of caregiving hours for both women and men, but more so for men. Fifteen percent of women caregivers were employed part-time, compared with 7.4% of male caregivers. The female caregivers employed part-time performed 4.6 hours of care per week on average; the male caregivers employed part-time performed an average of 2.3 hours of care. Female caregivers with full-time paid employment performed an average of 4.2 hours of care per week, whereas their male counterparts performed 2.6 hours. Three-quarters of male caregivers (70.5%) and almost half of female caregivers (46.8%) had full-time paid employment (Keating et al. 1999).

Twenty-five percent of female caregivers of seniors with functional limitations had children under age 15, compared with 32% of male caregivers. The presence of children under age 15 reduced the number of hours of caregiving more for women than for men, but women still performed more hours of caregiving for seniors than men. The study suggested that time spent caring for children competed with time spent caring for seniors (Keating et al. 1999).

Compared with the general population, somewhat higher proportions of married women and men, as well as women and men in common-law relationships, were caregivers of seniors with functional limitations; marriage does not reduce the likelihood of being a caregiver. Single caregivers, however, put in more hours of care than married caregivers, and single women performed more hours of care than single men. The only demographic category in which men provided more hours of care than women were widowed persons, but widowed men made up only 1.5% of male caregivers (Keating et al. 1999).

The levels of education of caregivers versus non-caregivers were not significantly different. Women with lower levels of education, though, tended to provide more hours of care, leading the authors of one national survey to postulate that women with higher levels of education may be in the position to reduce their caregiving hours by purchasing care (Keating et al. 1999).

3.7 CAREGIVING INTERFERES WITH ORDINARY LIFE MORE FOR WOMEN THAN MEN

Women caregivers were more likely than male caregivers to feel pressed for time. A marginally higher proportion of female caregivers than male caregivers reported having to make changes in social activities (47% versus 44%), change holiday plans (26% versus 25%), postpone plans to enrol in an education or training program (7% versus 5%), move in with the care recipient (7% versus 5%), move closer to the person being helped (15% versus 9%), and change sleep patterns (31% versus 26%) because of the care they provided (Cranswick 1997). The more hours of care women provided, the greater the impact their caregiving had on their lives (Keating et al. 1999).

3.8 WOMEN TRAVEL FARTHER AND MORE OFTEN THAN MEN TO PROVIDE UNPAID CARE

A University of Guelph study based on a national survey of work and family conducted by the Canadian Aging Research Network (CARNET) considered the impact of the distance between employed caregivers and their elderly relatives. Analysis of data for 1,149 men and women with eldercare responsibilities revealed a significant relationship between the distance from the elder and the average weekly number of hours devoted to eldercare. When the data were disaggregated by gender, however, the study revealed that only male caregivers were less willing to travel in order to care for a distant relative. Employed women caregivers were willing to travel farther and more often than employed male caregivers. The authors stated that eldercare affected the careers and family lives of female caregivers more significantly than those of men; women were more likely than their male counterparts both to travel in order to provide care and to squeeze more into already tight time schedules (Joseph and Hallman 1998).

3.9 MORE WOMEN THAN MEN PROVIDE MORE DEMANDING FORMS OF CAREGIVING

According to Kaden and McDaniel (1990), wives and daughters provided the bulk of the more demanding daily and weekly caregiving tasks; husbands and sons were more likely to assist with intermittent, sporadic tasks. Of people who received daily or weekly assistance from spouses, 77% was from wives and 24% was from husbands. For people who received daily or weekly assistance from their children, 87% was from daughters and 13% was from sons. The authors stated that the gender differences in the source of support (men more likely to be receiving care from wives, women from their adult daughters) is important because research shows that older people wish to avoid becoming dependent on their children; it is largely women who are being placed in this position.

The Canadian Study of Health and Aging (1994) reported the results of a sample of 9,008 elderly people living in the community and of 1,255 elderly people living in institutions in 36 urban centres and surrounding rural regions in Canada in 1991–92. The purpose of this study was to look at differences in caregiving for older people with dementia and those without. Of the 1,686 primary caregivers in the study, 1,472 were unpaid, mainly family members. All of the 214 paid workers were women, and 72% of the informal caregivers were women. Most primary caregivers were female and married. Seniors who were living in the community and were suffering from dementia were more likely than those without dementia to have a female caregiver (75% versus 66%). Wives were more likely to be the informal caregiver for seniors living in the community than in an institution, whereas daughters were more likely to be the caregivers of institutionalized seniors. Of the community-living dementia group, 24% of caregivers were wives, 13% were husbands, 29% were daughters, 10% were sons, and 24% were other family or friends. The mean age of the caregivers was 61.9 years. Of the community-living group without dementia, 29% of caregivers were wives, 20% were husbands, 30% were daughters, 12% were sons, and 9% were other family and friends. The mean age of these caregivers was 58.2 years. This study collected data about paid employment, use of

community services, satisfaction with services, and health of caregivers, but unfortunately these results were not disaggregated by sex. The study found that only 44% of the caregivers of the group with dementia, versus 95% of the caregivers of the group without dementia, were satisfied with services provided, and that depressive symptoms were twice as common among the caregivers of persons with dementia. Considering that women in the general population report significantly more depression than men (Health Canada 1999), it would have been interesting and useful to have sex-disaggregated data about depression among caregivers of persons with dementia. Such data could be used to determine how much of the depression in this group can be accounted for by the fact that women are overrepresented in this group, to provide avenues for further research about depression in women at large, and to determine to what extent women's depression is due to difficult caregiving tasks.

3.10 MORE WOMEN THAN MEN ARE CAREGIVERS OF SEVERAL PEOPLE WITH FUNCTIONAL LIMITATIONS

We may tend to think of the caregiving relationship as being between only two people — one caregiver and a recipient of care. However, many caregivers perform caregiving responsibilities for several people, and women do so more than men. Two-thirds of both the male and female caregivers cared for more than one senior with limitations. Almost 9% of female caregivers of seniors with functional limitations were caring for five or more persons at one time, compared with 5.5% of male caregivers (Keating et al. 1999).

3.11 CAREGIVING PRIMARILY NEGATIVELY AFFECTS THE HEALTH OF WOMEN MORE THAN MEN

The evidence about whether the health impacts of caregiving are more significant for women than for men is mixed, but most of the research points to a greater negative impact on women. Keating et al. (1999) found that caregiving affected the health of 27.5% of female caregivers and 10.6% of male caregivers.

A study by the Roeher Institute (2000b) compared the health of mothers of children with disabilities in its sample to the health of mothers in general as measured by the 1996 National Population Health Survey. Mothers providing care to children with disabilities were in considerably poorer health. For example, 40% of Canadian mothers reported their health as “very good” compared with 12% of mothers of children with disabilities. Over half of mothers in the Roeher sample reported symptoms of stress, such as anxiety, depression, disrupted sleep, headaches, isolation, frustration, fear, anger, agoraphobia, hopelessness, feeling overwhelmed, ulcers, fatigue, stomach aches, hypertension, and chronic pain. Three-quarters of the mothers said their role of giving care to the child with disabilities caused stress and tension in the family and had an impact on the child's siblings. These respondents also reported strains in their marriage and an inability to do things most families take for granted, such as planning holidays. Over 75% of the mothers providing care to a child with disabilities tried to seek support to deal with stress, the majority from peers (63%), counseling (over 50%), and medication (37%).

Many of the participants said it was not the child with disabilities that caused stress, but rather the lack of adequate community care and support.

Keating et al. (1999) found that eldercare creates a significantly greater burden for women than for men. Caregiver burden was assessed using measures that seek to determine psychological status, physical health status, feelings of stress, perceived health status, and related measures. This large-scale Statistics Canada survey found the following:

- Forty-five percent of caregiving women compared with 36% of caregiving men said they did not have enough time for themselves because of their caregiving responsibilities.
- Fifty-nine percent of caregiving women and 46% of their male counterparts felt stressed by their caregiving role and by trying to meet other work and family responsibilities.
- More caregiving women (25%) than caregiving men (19%) felt angry around the person for whom they were caring.
- One-third of women and men, although a slightly greater proportion of women (37%) than men (34%), wish that someone else would take over their caregiving responsibilities.
- More women (19%) than men (17%) admitted that they felt their caregiving role was a burden.

The finding that the caregiving burden on women is greater than that on men can be explained by the findings outlined in Section 3: compared with men, women spend a greater number of hours on care, perform the more difficult tasks of care, sacrifice more of their paid work time to perform unpaid care, and feel obligated by their social role to provide unpaid care; providing care may be less of a real choice for women than for men.

In a study using Manitoba data from 1991–92, daughters were more likely to have higher levels of caregiver burden than sons, and adult children who were employed reported higher levels of caregiver burden than those not employed, which suggests that trying to balance employment and caregiving adds to the burden caregivers experience (Hawranik and Strain 2000). Of 155 Manitoban caregivers of seniors interviewed in 1991–92 and again in 1996–97, both female and male caregivers reported significant changes in caregiver burden. Among spouses, only wives had increased levels of caregiver burden. Among adult children, sons had increased levels of caregiver burden (Hawranik and Strain 2000). Where the data seem to depart from other studies is on self-identified health ratings. Of 322 caregivers of seniors identified in the Manitoba Study of Health and Aging in 1991–92, 41% rated their health as “very good” and 51% as “pretty good.” Fourteen percent showed signs of depression as measured by the Center for Epidemiologic Studies Depression (CES-D) scale. Of 155 caregivers interviewed in 1991–92 and again in 1996–97, 88% had no change in self-rated health: however, there was an increase in possible depression and in caregiver burden. Husbands who were caregivers were more likely to have poorer self-rated health than wives (Hawranik and Strain 2000).

Adult caregivers of parents who reported using at least one home care service — such as homemaking or cleaning, in-home nursing, home-delivered meals, a day centre or day hospital, hospital respite, or nursing home respite — tended to have higher levels of caregiver burden (Hawranik and Strain 2000), possibly reflecting the more serious and deteriorated state of the care recipient.

One of the studies reviewed, a University of New Hampshire study, found greater caregiver burden among a certain group of men. This study examined the characteristics and caregiving experiences of friends and family members aged 18 to 49 caring for people with AIDS (PWA) in a number of U.S. cities. The largest group of caregivers in this age category were male friends of the PWA, a group not typically found among caregivers of persons with other types of illnesses. In general, gay or bisexual caregivers, caregivers who had traditional family ties to the PWA, men, and lower income caregivers reported the greatest caregiver burden. While level of caregiving demands represented the most influential predictor of caregiver burden, white and male caregivers in this particular study experienced greater caregiver burden, independent of level of involvement and other caregiver characteristics. Receiving instrumental support with caregiving buffered the impact of the number and volume of demands on the caregiver's subjective experience of burden (Turner and Catania 1997).

Many studies showed a relationship between the impaired cognitive state of the care recipient and increased caregiver burden or depression for the caregiver (Hawranik and Strain 2000). Caregivers who had to provide a great deal of assistance, for example, helping with the basic activities of daily living (ADLs) such as eating and bathing, reported higher levels of caregiver burden and depressive symptoms (Hawranik and Strain 2000).

An Australian academic study compared the grief responses of husbands and wives who cared for their partners suffering from dementia at home with those of husbands and wives who provided ongoing nursing home care (Rudd, Viney, and Preston 1999). Four psychological states of grief were examined: anxiety, sadness, anger, and guilt. Sixty spousal caregivers participated in the study, 30 husbands and 30 wives, with equal numbers of home and nursing home caregivers. Nursing home caregivers expressed significantly higher levels of sadness and guilt than home caregivers, but home caregivers expressed significantly more anger than nursing home caregivers. Wives who cared for their spouse at home were found to be the angriest group. Caregiving wives expressed significantly higher levels of anxiety, sadness, and anger than caregiving husbands. Other studies have found that caregiving wives (and women caregivers in general) tend to put more hours into caregiving and have to give up more of their financial and personal autonomy than husbands who do so. This could be a factor in the greater anger reported by women caregivers.

A British study published in the *International Journal of Geriatric Psychiatry* compared male and female caregivers of spouses with dementia. The levels of strain and morale of the wives were significantly worse than those of the husbands. The caregiving tasks undertaken by husbands and wives were qualitatively different. Wives were less able to tolerate the degree to which dementia sufferers depended on them. Wives were also more

likely to wish to leave caregiving to someone else and cited more reasons for wanting to quit. Caregivers of both sexes displayed a strong tendency to view women as generally better suited to the caregiving role, and wives felt a greater obligation to provide care. The authors concluded that attitudinal and social factors were the chief determinants of higher levels of strain and distress in wives; they were expected to do more and felt they had less choice about it (Collins and Jones 1997).

Stress was a major factor for caregivers in a large number of gender-sensitive studies. Stress-related results of caregiving included the following:

- breakdown of families or relationships (Campbell, Bruhm, and Lilley 1998; Jewitt 1995)
- abuse (Jewitt 1995)
- burnout (Campbell, Bruhm, and Lilley 1998; Morris, Robinson, and Simpson 1999)
- physical or emotional breakdown or illness (Campbell, Bruhm, and Lilley 1998); the development of specific ailments, such as ulcers, headaches, stomach aches, hypertension, and chronic pain (Roehrer Institute 2000b); or generally deteriorating health (Blakley and Jaffe 1999)
- role overload (Jewitt 1995; Keating et al. 1999) or feeling overwhelmed (Collins and Jones 1997; Roehrer Institute 2000b)
- sadness (Rudd et al. 1999)
- depression (Blakley and Jaffe 1999; Hibbard, Neufeld, and Harrison 1996; Jewitt 1995; Roehrer Institute 2000b)
- fewer friendships and other relationships (Hawranik and Strain 2000)
- losing one's identity (Campbell, Bruhm, and Lilley 1998)
- having "no life" or no social life (Blakley and Jaffe 1999; Campbell, Bruhm, and Lilley 1998)
- isolation (Blakley and Jaffe 1999; Campbell, Bruhm, and Lilley 1998; Hawranik and Strain 2000; Roehrer Institute 2000b)
- loneliness (Campbell, Bruhm, and Lilley 1998)
- financial insecurity (Campbell, Bruhm, and Lilley 1998; Jewitt 1995)
- fear (Campbell, Bruhm, and Lilley 1998)
- anxiety (Rudd, et al. 1999; Tremblay et al. 1998)
- exhaustion (Blakley and Jaffe 1999; Campbell, Bruhm, and Lilley 1998; Tremblay et al. 1998)
- sleep disruption (Keating et al. 1999; Roehrer Institute 2000b; Tremblay et al. 1998)
- fatigue (Roehrer Institute 2000b)
- helplessness (Campbell, Bruhm, and Lilley 1998) or powerlessness (Blakley and Jaffe 1999)
- desperation (Campbell, Bruhm, and Lilley 1998)
- confusion (Campbell, Bruhm, and Lilley 1998)
- anger (Jewitt 1995; Keating et al. 1999; Roehrer Institute 2000b; Rudd et al. 1999)

- guilt¹¹ (Blakley and Jaffe 1999; Campbell, Bruhm, and Lilley 1998; Rudd et al. 1999)
- grief (Jewitt 1995)
- denial (Jewitt 1995)
- frustration¹² (Blakley and Jaffe 1999; Campbell, Bruhm, and Lilley 1998; Hawranik and Strain 2000; Roeher Institute 2000b)
- not enough time to engage in caring for one's own (the caregiver's) health and well-being (Blakley and Jaffe 1999; Campbell, Bruhm, and Lilley 1998)

The stress on caregivers is partly due to the fact that assessments for home care do not take into account the capabilities and limitations of the caregiver and the family situation. Caregivers are expected to do more than they are able (Campbell, Bruhm, and Lilley 1998; Chapman 1995).

Tremblay et al. (1998) conducted a three-year Quebec-based study of the health impacts of caregiving on women caregivers of persons who needed temporary or permanent assistance with daily living; these researchers paid particular attention to support systems available to caregivers through community groups and formal institutions. The study involved a literature review and semi-structured interviews with female caregivers. The authors discussed the trend in Quebec toward deinstitutionalization and assigning an increasing number of responsibilities to families, drawing on conceptions of unconditional love, sacrifice and duty. The authors offered these explanations:

- Because of the division of responsibilities along gender lines, women are largely expected to provide personal care for dependents and are seen as better suited to interpersonal relationships and support.
- As this is a societal norm, it is not then surprising that women take on this role.

¹¹ Guilt was a factor for a number of caregivers — guilt over giving birth to a child with disabilities, guilt over being healthy when the other person is ill, guilt about not understanding the other person's illness, guilt over not making the right choices about medications, health professionals, or the use of health facilities (Blakley and Jaffe 1999).

¹² Factors contributing to frustration were dealing with a “maze of bureaucracy” (Campbell et al. 1998), the denial on the part of function-impaired elders that they needed help (Hawranik and Strain 2000), and the demanding and repetitive nature of caregiving tasks (Blakley and Jaffe 1999).

- Women thrust into caregiving must develop strategies to handle the multiple pressures of their personal life, domestic and family responsibilities, and social and professional life within a context of inflexible public and private services.

The authors reviewed literature about health impacts, including physical exhaustion and the stress, worry, and sleeplessness associated with tensions and imbalances in paid work, family, and personal lives.

Tremblay et al. (1998) found from preliminary interviews that institutional aid was available to health care users rather than their informal caregivers, that services in the Saguenay–Lac-Saint-Jean area were limited, that volunteer caregiving was primarily an individual matter rather than coordinated through organizations, and that most of the community health and social service centres in the region (known as CLSCs) did not have support services for caregivers, particularly a place for caregivers to go to share their experiences and be heard in decision-making. Caregivers themselves were not considered to be clients of health and social services but rather to be informal resources. The authors recommended that CLSCs partner with organizations representing caregivers. The authors implied that inadequate services for caregivers and care recipients may be threatening the health of caregivers.

3.12 WOMEN HAVE GREATER SUPPORT NETWORKS THAN MEN, BUT THOSE NETWORKS ARE NOT ALWAYS HELPFUL

Social support is one of the determinants of health. Hibbard, Neufeld, and Harrison (1996) studied gender differences in the support networks of caregivers, reported in the *Journal of Gerontological Nursing*. They interviewed 20 women and 20 men, primarily white, middle-class people. Most of the male caregivers were spouses, whereas most of the female caregivers were daughters. For women, age, years of caregiving, and socioeconomic status were not significant predictors of the size of their social network. Younger men and men of higher socioeconomic status, however, had much larger available social networks than other men. Women caregivers experienced significantly more conflict, particularly with family members. Intrafamily conflict was a predictor of caregiver depression. The authors postulated that the sources of the conflict were excessive or multiple role demands and the greater provision of personal care by women. The study found that men and women were at risk of insufficient support in different ways, men — particularly older, lower income men — as a result of having limited social resources on which to draw and women because of the many sources of conflict they experienced. The authors concluded that formal home care providers should recognize that an unpaid caregiver's social network can be a source of conflict and be aware of the importance of the role of social support as a means of sustaining caregivers in their daily activities.

3.13 SOME FACTORS CONTRIBUTE TO CAREGIVERS' WELL-BEING

Some positive consequences of caregiving are outlined in the literature. Many caregivers find the work rewarding. Ninety percent of women caregivers of seniors and 86% of male caregivers of seniors reported stronger relationships with the care recipient as a result of the caregiving (Keating et al. 1999).

Lauzon et al. (1998) conducted a critical overview of the literature on caregivers, with a focus on gender-sensitive studies involving caring for seniors. The authors found that the majority of studies dealt with health effects of caregiving, using a theoretical outlook that focused on stress and coping rather than examining the larger context of the caregiving experience. They also found that the majority of studies stressed the negative aspects of caregiving. They classified 79 studies conducted between 1980 and 1997, including articles, books, and doctoral theses, into structural themes. The authors chose to highlight the findings of a few studies: good relationships between the caregiver and the care recipient benefitted the caregiver's health, as did supportive relationships in general, recognition from the caregiver's family, the rapid adjustment of the caregiver toward the ethic of caring, attainable goals in caregiving that were respected by health professionals, and ascribing meaning and significance to the caregiving experience. Three strategies were identified as being good for caregivers' well-being: establishing clear limits to caregiving, finding a method of reconciling various responsibilities, and maximizing the potential of the care recipient.

3.14 CAREGIVING INTERFERES WITH PAID WORK FOR WOMEN MORE THAN MEN

A Statistics Canada survey of caregivers of seniors found that more than half of female caregivers (55%) reported that the care had repercussions for their paid work, while less than half of male caregivers (45%) reported the same effect (Cranswick 1997).

In its multi-province study of caregivers, the Roeher Institute (2000b) found clear evidence that the caregiving role limits the participation in the paid labour force, the economic security, and the choices of mothers of children with disabilities. Half of the mothers worked outside the home, and 30% had full-time paid employment. Those who did not do full-time paid work felt that not working for pay, or working reduced hours, placed an economic strain on the family, but they felt they had little choice. Ninety percent cited their caregiving responsibilities as the reason they could not look for paid work. The women working for pay on a part-time basis cited their caregiving responsibilities as their reason for this "choice." One mother was told by her workplace to make a "choice" between her family and her job. Over 50% of the mothers had to leave the paid labour force at some point to care for their child with a disability. Over 35% had changed jobs or reduced their hours to meet their child's needs. Over 30% of the women had encountered difficulties with employers, educators, or trainers because they had to care for a child with a disability. Some women looked at their caregiving as a 24-hour-per-day job and stated that they would have liked some remuneration or recognition. One mentioned worry over her lack of a pension after years of caregiving.

A study of 396 female and 316 male employees who provided unpaid eldercare in urban and rural areas across Canada examined the extent of their eldercare involvement, the

extent to which their family responsibilities interfered with paid work (FIW), the extent to which their work interfered with family responsibilities (WIF), job satisfaction, job costs (e.g., missed meetings), and absenteeism. Eldercare involvement was significantly associated with FIW for women but not men because women performed eldercare of a different nature and quantity. The women in the sample spent an average of 39.2 hours per week at their paid job, and 5.7 hours helping at least one older relative. The men spent an average of 48.3 hours per week at their paid job and 4.9 hours per week assisting an older relative. Women provided more assistance with the activities of daily living. Men's eldercare involvement (e.g., help with finances) could more often be dealt with outside of paid work hours. FIW among women was related to job dissatisfaction and absenteeism. Among men, it was related to job costs and absenteeism. The study concluded that eldercare responsibilities have an impact on the workplace, particularly for women, by creating conflict between paid work and family (Gignac, Kelloway, and Gottlieb 1996).

In a sample of rural caregivers, many had given up paid employment to provide care. Fewer than a quarter had paid employment. Almost half of those who were not currently employed said they had left a paying job or changed jobs because of caregiving responsibilities. The authors calculated that if the caregivers were paid \$10.90 per hour for the average number of hours they worked, each would receive \$92,000 annually (Campbell, Bruhm, and Lilley 1998).

3.15 CAREGIVING INVOLVES FINANCIAL COSTS FOR MEN AND WOMEN, BUT MORE LONGER TERM COSTS FOR WOMEN

Morris, Robinson, and Simpson (1999) reported that the financial costs associated with dealing with illness, frailty, or disability at home, such as the costs of medical equipment, special meals, renovations to accommodate disabilities, repairs and maintenance in the care setting, and sometimes prescription and non-prescription medications, were largely paid by care recipients, their families, and unpaid caregivers, and sometimes by paid home care workers. The amount of public funding for these costs varies by jurisdiction.

Cranswick (1997) found that a slightly higher proportion of male caregivers (46%) than female caregivers (42%) reported incurring extra expenses because of the care they provided. These extra expenses, however, were those related directly to caregiving and did not include the opportunity costs of lost wages, benefits, pension credits, and so on.

A number of U.S. studies examined the cost of informal caregiving, but they do not report the costs by sex. For example, a University of North Florida study found that the estimated annual value of uncompensated care of relatives in 1990 was US\$18 billion. The authors found that 9% of family caregivers leave the labor force to provide care, 29.4% adjust their paid work schedules, and 18.1% take time off without pay. Thirty-two percent of all family caregivers were poor or near-poor, as measured by the U.S. federal poverty level (Robinson 1997). A Montefiore Medical Center (New York) study measured the market value of the care provided by unpaid family members and friends to ill and disabled adults, estimated at US\$196 billion in 1997. This figure substantially

exceeds U.S. national spending for formal home health care (US\$32 billion) and nursing home care (US\$83 billion) (Arno, Levine, and Memmot 1999). Statistics Canada collects Canadian data on unpaid work, which includes housework and all kinds of care, including care of non-disabled children. According to Statistics Canada, women in Canada perform between \$234 billion and \$374 billion worth of unpaid work per year (1995). As women are the majority of unpaid caregivers of persons with functional limitations, working longer unpaid hours and giving up more paid employment than men caregivers, it stands to reason that the long-term economic impact of caregiving is much greater for women than men, but these costs have not yet been fully quantified.

Fast et al. (1997) laid the conceptual groundwork for a Canadian study that would calculate the costs of unpaid caregiving of people with short- or long-term functional limitations, including costs associated with lost hours of paid employment, pension benefits, missed educational opportunities, and other costs in addition to the immediate financial costs of supporting or helping a care recipient. These researchers, however, did not consider gender and concentrated only on eldercare. No study incorporating a gender analysis of all forms of caregiving of all types of care recipients has yet been published in Canada.

Armstrong and Kits (2001) were among the few authors that outlined the history of state financial support for caregivers. According to the authors, Nova Scotia provided compensation to caregivers between 1984–94, mainly to young women in rural areas whose “wage” was considerably less than minimum wage for the amount of work they performed. The program was also means tested. Quebec provides up to \$600 to means-tested caregivers to buy respite care. Since 1998, the federal government has offered the Caregiver Tax Credit, which allows a caregiver to claim up to \$400 if the claimant’s annual income is under \$13,853. The authors stated that these programs are inadequate to meet the needs of caregivers, and benefits delivered through the tax system have little meaning to women whose income is so low that no taxable income exists to which to apply the credit. The authors also revealed that although some jurisdictions have employment or labour standards legislation that allows short-term and unpaid leave, no jurisdictions require employers to provide caregiver leave. As a number of other studies have done, this study pointed out that women’s caregiving work in the home is invisible and therefore of less concern to policy-makers.

3.16 MOTHERS ARE OVERWHELMINGLY THE PRIMARY CAREGIVERS OF CHILDREN WITH DISABILITIES AND FACE SPECIAL CHALLENGES

The Roeher Institute is a national institute for the study of public policy affecting persons with intellectual and other disabilities. Its study of primary caregivers (96% of whom were mothers) of children with disabilities consisted of 50 interviews with caregivers in Saskatchewan, Manitoba, Ontario, Quebec, and New Brunswick (Roeher Institute 2000b). Sixty percent of the caregivers lived in urban areas, and 40% in small communities or rural areas. Only 6% of the sample were visible minority women. Three-quarters of the families were headed by two parents, a quarter were female-led single-parent families. Family income ranged from low to high. Only one family relied

on social assistance. Ninety percent of the children had multiple disabilities, including physical and mental disabilities. Mothers spent on average 50 to 60 hours per week on providing personal care, advocacy, coordination of services, and transportation directly related to the child's disability, of which about 3 to 4 hours per day involved hands-on personal care, such as bathing, feeding, providing medical assistance, and so on. Some of the children had high needs and required about 18 hours per day of personal care, some of which was provided by paid workers. One mother spent 17 hours per week just coordinating and advocating support services for her daughter, not including time spent in transportation to and from programs and appointments. It seemed that some of the available services were disjointed and required coordination: the majority of mothers reported involvement in three to five community agencies or organizations that supported their children. Sixty percent of the mothers received some support from paid staff, who performed personal care tasks an average of two to three times per week.

The Roeher Institute (2000b) reported that although the families were of different backgrounds and circumstances, most had a common experience of non-responsive or inadequate services and supports. Over 70% of the mothers were dissatisfied with the amount of support they received. Ninety percent said that their top need to support their children in the community — adequate, flexible respite care provided by trained and committed personnel — was not being met.

Negative community attitudes were also a barrier for half the families. As one mother put it, "The community is terrified of these kids." Less than 25% of the women had any extended family supporting them, and if they did, family support tended to be sporadic. Twelve percent of the women felt that if, for whatever reason, they were unable to perform their caregiving role, they would have no one at all to turn to. Fifty-six percent of the mothers belonged to a support group or network. Of those who did not, 40% would have liked to. On the positive side, women reported developing new skills, sensitivity, and confidence and discovering their own strengths and talents as a result of their challenging caregiving experience (Roeher Institute 2000b).

In addition to their huge care load, 85% of the mothers were engaged with the education system in advocacy on their child's behalf. In particular, they were dissatisfied with the physical, occupational, and speech therapy supplied through the education system. Budget cuts to education were a concern for many mothers, who were worried that these would create even more struggles for them. Some of the children already did not qualify for needed speech, occupational, physical, and recreational therapies offered through the schools, and these therapies were often sporadic and time limited. Some schools did not offer these services at all, and for one family, the closest available service was two hours away. A quarter of the children were enrolled in child care. The largest frustration for mothers in terms of child care was finding a program that would accept a child with disabilities. Some programs that did were not able to meet the child's needs. Only 12% of the families had access to after-school care: barriers included the unavailability of services, the prohibitive cost of private services, the lack of reliable and qualified care, staff's lack of knowledge about the disability, and high staff turnover among in-home workers who also tended to lack training and skills. One participant reported 15 changes in staff over a two-and-a-half-year period and the limitations of these workers, who could

not administer medications. Thirty percent of the families could not obtain community services due to a lack of transportation. Where transportation support services existed, mothers had concerns about the attitudes of drivers and the inconsistency and inflexibility of service. Health care cutbacks were also a concern; the mothers pointed to cutbacks as the reason why specialized medical and therapeutic services were becoming even more difficult to obtain. Many health professionals also did not grasp the strain the parents were under, focused on tests and diagnoses rather than the total well-being of the child, and were insensitive, even blaming mothers for the disability (“What did you do? Fall? Drink? Paint?”) or telling a medical student present in the office, “This child will probably be dead in a year,” without ever before having mentioned the possibility of the child’s death to the parents (Roeher Institute 2000b).

A University of North Carolina study found that most caregivers of adults with mental disabilities were older women. The authors interviewed 235 older mothers caring for adults with mental disabilities. Mothers were less likely to use day services for their daughters. Mothers of mentally disabled daughters were more likely to feel burdened by caregiving, even though they received the most help from disabled daughters with household tasks. The authors concluded that gender differences have implications for outreach to and services for these families (Fullmer, Tobin, and Smith 1997). Caregivers’ different attitudes toward female care recipients may also have implications for the quality of care women receive.

3.17 WOMEN AND MEN CARE RECIPIENTS ARE SUBJECT TO VIOLENCE AND RISKS TO THEIR PHYSICAL SAFETY, BUT WOMEN CAREGIVERS MAY BE AT GREATER RISK THAN MEN

In searching for material for this section, it became clear how many studies exist on elder abuse and abuse of people with disabilities that do not take gender into account. Those studies that mentioned gender tend to be about women only.

Elder abuse or abuse of older adults is the “mistreatment of older people by those in a position of trust, power or responsibility for their care.” Such mistreatment can include physical, psychological, and financial abuse and neglect, which is the failure of a caregiver to meet the needs of an older adult who is unable to meet those needs alone. Neglect includes behaviours such as denial of food, water, medication, medical treatment, therapy, nursing services, health aids, clothing, and visitors. According to Health Canada, approximately 4% of older Canadian adults living in private homes reported experiencing abuse or neglect, but these data are not disaggregated by sex. Information was neither collected nor reported about what proportion of these people experienced functional limitations, what proportion of these people were receiving paid or unpaid care, and whether they were being abused or neglected by paid or unpaid caregivers or by other family members or professionals. The publication reported that males are more likely to be perpetrators of physical abuse, and women are more likely to be perpetrators of neglect and financial abuse (Swanson 1998).

Saxton et al. (2001) investigated the perceptions and experiences of women with physical

and cognitive disabilities related to abuse by formal and informal providers of personal assistance. The authors conducted focus groups and individual interviews with 72 women from age 19 to 70 to explore how they defined personal assistance abuse, the barriers they faced in handling abuse, and the strategies they recommended to prevent abuse. Key themes that emerged included the following: (1) the role of social and personal boundary confusion and power dynamics within the personal assistance services relationship; (2) expanded forms of abuse experienced by women with disabilities; (3) the complexity of using family and friends as care providers; (4) personal, social, and systemic barriers that impede women's response to abuse; and (5) the benefits of supports that validate women's experiences and bolster their capacities to prevent and manage abuse. The title of the study, "Bring my scooter so I can leave you," exemplified the dependence many women with disabilities have on care providers and how difficult it can be to get away from an abusive person one depends on for mobility and other forms of assistance with everyday tasks.

One gender-sensitive home and community care study reviewed in this paper asked questions about violence and reported that some care recipients had experienced financial abuse and harassment by paid and unpaid caregivers and had little recourse (Morris, Robinson, and Simpson 1999). More often than not, home and community care studies do not include questions about violence and abuse.

A number of studies (Côté et al. 1998; Morris, Robinson, and Simpson 1999) mentioned that women caregivers are at risk of violence, particularly by care recipients who are mentally ill or with whom there had been a preexisting family relationship of abuse. Although male caregivers may also be at risk of some violence, average physical differences in strength between women and men, and different gender roles in terms of responding to physical violence, may result in more men than women being able to successfully defend themselves against physical attack by a family member to whom they are providing care.

One study found that care recipients, paid home care workers, and unpaid caregivers all had health, safety, and human rights concerns (Morris, Robinson, and Simpson 1999). The physical safety of care recipients and of paid and unpaid caregivers was also at risk due to the overwork and inadequate training of paid and unpaid care providers. Unpaid caregivers were not covered under any workers' compensation plan if injured at their unpaid job.

3.18 CAREGIVERS AND CARE RECIPIENTS IN IMMIGRANT, REFUGEE, AND VISIBLE MINORITY COMMUNITIES FACE RACISM AND LANGUAGE AND CULTURAL BARRIERS

Most studies that look at immigrant, refugee, and visible minority communities tend to lump these communities together without providing any separate analysis as to how specific communities might be affected.

Although a few Canadian studies are specifically about race or ethnicity and caregiving or care receiving, studies in this area are almost exclusive to the United States. This is

unfortunate because the experience of racism in mainstream health and social service agencies, and different cultural expectations and access to networks, could be a factor for both caregivers and care recipients belonging to immigrant, refugee, or visible minority communities (Morris, Robinson, and Simpson 1999). Although U.S. health and social data are useful as a starting point, the Canadian context has major differences: different immigration policies and settlement practices; different relationships between race, income, and access to health care services; different health care systems; different approaches to community and collective responsibility toward citizens in need; different racial and ethnic mixes in the population with different backgrounds and histories within the country; different sizes; and perhaps differences in the degree of social cohesion among particular ethnic and racial minority communities. As well, it is important not to treat immigrant and visible minority communities as being uniform because enormous cultural and other differences exist between them that might have an impact on their receipt of informal or formal care.

Armstrong and Kits (2001) made an important point about not assuming that ethnic and racial differences in living arrangements for older and disabled relatives are necessarily due to cultural differences rather than to low incomes, lack of pensions, and immigration sponsorship rules, for example.

Morris, Robinson, and Simpson (1999) collected information about the race, ethnicity, and mother tongue of the caregivers and care recipients they interviewed. These researchers found that both caregivers and care recipients belonging to visible and linguistic minority groups experienced racism in their access to home care services. For example, one disabled woman of colour was told by her home support worker, "As an immigrant, you should be grateful that you are here and for the services you receive." The authors, who also interviewed managers of home care agencies, found that no mechanism to deal with complaints of racism exists, no anti-racism training is provided to home care staff, and, if any linguistic/racial/ethnic matching of staff to recipients occurs, it is done on an ad hoc basis.

A University of Pennsylvania study investigated potential differences in depression, stress and rewards, and the quality of the parent care relationship between 261 white and 56 African American daughters and daughters-in-law who were providing care for an impaired parent or parent-in-law (White et al. 2000). African American women reported less stress and more rewards in the parent care role than white women did. Race did not have a significant effect among caregivers on depression, ability to perform the caring role, or the quality of their relationship with the parent. It is possible that for African American women, caring for a parent was among the least of their stresses, or that they may have a greater family network on which to rely. No similar Canadian research has been done.

Talbot, Soucy, and Soave (1998) conducted 30 interviews with women immigrant family caregivers of Haitian, Asian, and Italian origin in the province of Quebec. The women were all informal caregivers of adults or children with at least one physical disability. Other studies of caregivers in Canada have found that such caregivers felt isolated. Talbot, Soucy, and Soave (1998) found that isolation was compounded by women

immigrant caregivers' differences from mainstream society in language and culture, and by their difficulties in negotiating the health care system. Most of the families received some kind of formal support service, such as nursing, social work, and some medical services in the home, as well as some respite, child care, and transportation. Linguistic difficulties between service providers and the informal caregivers sometimes led to misunderstandings about cost. The five main areas of dissatisfaction identified by women immigrant caregivers were as follows: the turnover of paid home care personnel; lack of information about the physical condition, diagnosis, and pain management procedures for their care recipient; lack of support for the care recipient's family members; lack of emotional support; and lack of help or orientation toward recreational activities or any activity designed to reduce isolation. In fact, these points are very similar to those made in other studies of caregivers in general, except that the linguistic and cultural differences of the caregivers in this study would have made finding the support they needed even more difficult. The authors noted that some of the obstacles are rooted in inadequacies in Canada's immigration settlement system, which in their view does not provide new Canadians with enough language skills and information or training about the health care system. Some of the obstacles are related to the rigidity of the health care system itself, to its being unable or unwilling to provide health services in the non-official languages of significant segments of the population, to provide adequate access to transportation, to cover the costs of care, or to train health professionals to improve their attitudes toward immigrant and visible minority communities. Another flaw in the system, according to the authors, was the lack of knowledge about the health care system on the part of community organizations that might be in a position to help members of immigrant and visible minority communities. Unfortunately, the authors did not give an analysis of how the Haitian, Italian, and Asian groups might have differed from one another, or of whether the experience of racism and linguistic and cultural difficulties was the same or different for each group.

A McMaster University study assessed the gender and ethnocultural proportion of clients (largely seniors) receiving services from three home care health agencies in Southern Ontario (Majumdar, Browne, and Roberts 1995). Providers from the three agencies were asked to recall clients served in the previous two weeks and to describe them in terms of race, language, sex, age, and disability status. White, English-speaking clients comprised 88.3% of the sample. The remaining 11.7% were white, non-English-speaking (7.8%), visible minority (2.8%), francophone (0.77%), indigenous (0.22%), and Hispanic (0.11%) clients. Sixty-three percent of clients were women and 34% were men. The majority (66.6%) of clients were over 65 years old. The 11.7% of clients who were identified as "multicultural" in the three home care agencies constitute an underrepresentation of the multicultural proportion (24%) of the population in the Southern Ontario region. This study provides empirical evidence that home care service agencies are not being used as much by and may not be as accessible to people who belong to visible or linguistic minority groups. It also points to the possibility that women in these communities may face a greater burden of unpaid care to compensate for fewer paid services and support.

There is very little in the way of gender-sensitive research on home and community care

in terms of how women and men in immigrant communities are affected. Out of 131 sources listed in a recent Canadian synthesis paper about research and policy on immigrant women's health, only one was specifically about home and community care or caregiving, and this was a doctoral dissertation rather than a publication (Mulvihill, Mailloux, and Atkin 2000). However, studies about immigrant women and men's access to health care in general can serve as a starting point.

The Quebec-based Alliance des communautés culturelles pour l'égalité dans la santé et les services sociaux (ACCESSS), in conjunction with the Centre d'excellence pour la santé des femmes (CESAF), released a study on migration and aging, with a focus on immigrant women. This study confirms the findings of the others that older immigrants face significant challenges in accessing the health care system because of language barriers, and that adaptation to new systems is especially difficult (a) if the migration was involuntary (such as in the case of a woman whose husband decided, against her will, that the family should emigrate, or a refugee who would have preferred to remain in her own country but could not because of war or persecution) or (b) if the differences between Canada and the country of origin are great. Immigrants might have lost a valuable support network when they left their country, a loss that the authors concluded was more debilitating to women because these networks tend to be more central to women's lives. Women perform the role of informal caregiver in 70% to 80% of immigrant families. The study did not focus in particular on home and community care (Mayatela et al. 1999).

No gender-sensitive home and community care literature exists about care recipients who are or were refugees. The profound mental health implications of refugees' experiences of persecution, war, torture, loss, and exile are well documented. These could be a factor for refugee care recipients, particularly when strangers come into the home. As well, many refugees may not have the same kind of relationship toward authorities and the state as Canadian-born people. Refugees from totalitarian countries where the state is involved in violence against and torture of citizens may find it more difficult to interact with formal home care services and support systems. There are also particular gender-based implications. Female refugees may be more likely to have experienced gang rape by people in authority and others, and therefore to suffer the particular physical and psychological consequences of such an experience. Many issues of access to health care have been documented in a synthesis paper on policy and research relevant to immigrant and refugee women's health in Canada (Mulvihill, Mailloux, and Atkin 2000). Research specifically about how refugee women and men experience formal and informal home care would be valuable, especially if it also examined how to make home care systems more accessible to them.

3.19 ABORIGINAL WOMEN CAREGIVERS AND CARE RECIPIENTS ARE DISADVANTAGED AND POORLY SERVED

There are a few studies about how Aboriginal women experience the health care system and support services in general, and there are a few overviews (containing little or no mention of gender) of Aboriginal home care. No gender-sensitive data about Aboriginal

women and men as care recipients are available, although certain implications can be drawn from what is known about Aboriginal home care.

Of all the gender-sensitive home and community care studies reviewed, only Morris, Robinson, and Simpson (1999) specifically collected data about Aboriginal caregivers and care recipients and performed an analysis that specifically examined the differences between Aboriginal and non-Aboriginal people's experiences of home care. In recent years, Health Canada has begun to transfer responsibility for health services to some individual bands. The study found, through interviews with representatives of organizations such as Aboriginal Nurses of Canada, that home care was not taken into account in the planning of these transfers. Unless they had the foresight to ask particularly for home care funds, bands were told that no more funds were available. The study also found that although Aboriginal men and women are affected, like everyone else, by early discharge from hospitals, home care services are not available on most reserves and in remote communities, despite the existence of a limited Health Canada program. According to the study, this has two implications for women: (a) untrained, unpaid women are the home care system in many of these communities and are expected to provide care, often in poor, overcrowded, and unhealthy housing conditions; and (b) as the majority of care recipients, women experience the result of inadequate service. Métis and men and women of Aboriginal ancestry who are not "status Indians" are covered by the same provincial programs as other Canadians, but these programs are not culturally sensitive to Aboriginal peoples. Another particular area of concern identified by the study is the lack of appropriate services available to HIV-positive Aboriginal women and men in urban centres.

3.20 LESBIAN AND GAY CAREGIVERS FACE ADDITIONAL STRESS AND BARRIERS

Some qualitative research specifically about or inclusive of lesbians and gay men as caregivers and care recipients exists, but it includes no statistical profiles. The literature about gay men focuses primarily on people living with AIDS, although gay men, like

other men, also presumably need care for cancer, advanced age, disability, and other conditions.

Aronson (1998) interviewed eight lesbian caregivers of lesbians who needed care because of an illness or disability. The study took place in Ontario, and all participants were white, employed, middle-income, urban women between the ages of 30 and 60. She concluded that lesbians live much of their lives outside heterosexual kinship structures, and may be less likely to turn to their families for support because of heterosexism or rejection. Lesbian caregiving can go beyond partners and friends to community networks. The author gave as an example a spontaneous network of support that developed around a Hamilton lesbian with breast cancer. Aronson pointed out that the type of disease or disability might be a factor in the amount of support that can be mobilized around an individual; for example, breast cancer is highly politicized, but someone suffering from chronic fatigue may not be able to build up such a network. Other factors affecting lesbians included the following:

- Lesbians had mixed experiences with institutions. Sometimes lesbians were supported and respected, but at other times they were not. This variation in treatment led to doubt and anxiety.
- Study participants frequently referred to heterosexist bias in the health care system, workplace, and legal system as barriers to caregiving. For example, some study participants reported feeling that they could not disclose to health professionals their true relationship to the person in need of care, and one individual reported passing herself off as a sister instead of a partner in order to ensure being able to see her partner in hospital. Some participants reported that people at work did not understand why they were taking so much time off to care for a “friend.” One individual reported losing a court battle to care for her partner, who was physically and cognitively impaired after a car crash, because the partner’s father objected to the relationship.
- Because lesbians are often poorly treated by institutions, a greater obligation is placed on lesbian partners and friends to care for an individual at home, in order not to expose her to bias and rejection.
- Little societal support exists for caring relationships between friends.
- Even lesbians’ commitment to care for their own partners was sometimes not taken seriously by their own friends.
- Friends who act as caregivers in supportive networks may presuppose that other friends in the network have the time, money, political skills, and institutional connections to make the caregiving work. Material resources are necessary to the operation of supportive networks.
- Gendered expectations that women will provide unpaid caregiving labour in the family applied to lesbians too. Lesbians’ relationships with partners were not taken as seriously as their siblings’ commitments to opposite-sex partners, and so lesbians may be more expected to care for their own parents than are their heterosexual siblings.

- Lesbians also experienced many of the same conflicting emotions and stresses experienced by other caregivers and derived both pleasure and distress from caregiving. One participant said she felt she lost her life and identity while caregiving.

As mentioned in the section on health impacts (Section 3.11), Turner and Catania (1997) found that being a gay or bisexual caregiver of a person living with AIDS was a predictor of caregiver burden, particularly if the caregiver was male. Caring for someone with a stigmatized disease associated with one's own community may be an additional stress factor in caregiving. In a study of U.S. racial minority women living with AIDS, all the caregivers, both men and women, reported the emotional burden of not revealing the HIV/AIDS diagnosis (Baker, Sudit, and Litwak 1998).

No mention is made in the literature of bisexual or transgendered recipients of care. Therefore, we do not know how similar their experiences are to those of gay and lesbian individuals.

3.21 THE BURDEN OF CAREGIVING IS GREATER FOR RURAL WOMEN THAN FOR URBAN WOMEN OR RURAL MEN

A study published by the Maritime Centre of Excellence for Women's Health focused on the needs of rural caregivers in Nova Scotia (Campbell, Bruhm, and Lilley 1998). This study included Black, Aboriginal, and Acadian participants. Although the study was open to male participants, in a sample of 46, all caregivers who came forward were women. The study found that, when compared with the needs of and resources available to caregivers in urban areas, the needs of caregivers in rural areas are likely to be greater, and the resources available to them fewer. Of the rural caregivers, 15% provided 24-hour care with no relief, and 63% had only occasional relief. Most of the rural caregivers expressed frustration and dissatisfaction and had little recourse to government services. This study found that these women were primary caregivers and were central to the home care system, rather than peripheral to it.

The finding that women in rural areas are more likely than either men in rural areas or women in urban areas to provide unpaid care is borne out by the Statistics Canada GSS. In urban areas, female caregivers of seniors with functional limitations provided an average of 4.7 hours of care per week; in rural areas, they provided an average of 6.0 hours of care per week. By contrast, their male counterparts in urban areas provided an average of 3.1 hours of care per week, and, in rural areas, an average of 2.9 hours of care per week (Keating et al. 1999).

Campbell, Bruhm, and Lilley (1998) point out that Canadians living in rural areas tend to have on average less education, lower incomes, and higher rates of unemployment, illiteracy, and dependence on social assistance than Canadians living in urban areas. Rates of long-term disability and chronic illness are also higher in rural communities than in cities. The proportion of elderly people is higher in rural Canada. The higher numbers of elderly and disabled Canadians in rural areas, coupled with dwindling health services,

place a greater demand on rural family caregivers. Resources for rural caregivers are minimal to nonexistent. People in rural areas also tend to be more conservative and traditional, which leads to an even greater expectation being placed on rural women to fulfill traditional roles as unpaid caregivers. The isolation felt by most caregivers is intensified in rural areas by a lack of services, transportation, and support networks (Campbell, Bruhm, and Lilley 1998).

According to a Statistics Canada survey, both female and male seniors in failing health who lived in rural areas were statistically more likely to receive assistance than those in cities. The suggested explanation was that seniors in rural areas are more likely than those in urban areas to have extensive, closely knit, informal networks and a stronger sense of community (Keating et al. 1999). This explanation is viewed by Blakley and Jaffe (1999) as a stereotype that contributes to the lack of resources for home care in rural areas.

Blakley and Jaffe (1999) of the University of Regina conducted a study of the impact of health care reforms on rural women informal caregivers in Saskatchewan. In the literature review in their study, they discussed the context of the closing of hospitals and long-term care facilities in rural Saskatchewan, the deinstitutionalization of people who are chronically ill or disabled, the scarcity and increasing centralization of respite and physical therapy services, and the shift from hospital to home care. In that province, regional health districts are responsible for home care, and service levels and eligibility vary by district. Some services that would be available at no cost to people receiving care in hospitals is not available free of charge to people receiving care at home. Family caregivers as a stakeholder group are not represented on health district boards, and policies that affect family caregivers are made without consulting them. The authors reported that assumptions are made about women being available and suitable for unpaid caregiving work; about the strong ties and large families in rural areas in contrast to urban families today having few relatives in the community; about financial stability in rural areas, when in fact the financial situation of many rural families is poor; about the lower cost of living in rural areas, which does not take into account hidden costs such as transportation; and about idyllic rural settings, which may in fact be isolating and lacking in social resources.

Blakley and Jaffe (1999) interviewed 53 women who were rural informal caregivers in the North Valley Health District in Saskatchewan. The area is depopulating due to out-migration and has lost essential services, such as hospitals, banks, and postal outlets. Over one-fifth of the population is over age 65. The caregivers interviewed were between the ages of 28 and 87, about half had gross family incomes of less than \$30,000, and of these more than half had gross family incomes below \$15,000. The age of the care receivers was between 2 and 98, with the median age being 70. Nineteen of the interviewees were mothers caring for ill or disabled children, 14 were daughters caring for parents, and 20 were wives caring for husbands. Some had been caregiving for over 20 years. The majority of the caregivers lived in the same home as the care receiver. About 40% of the caregivers had formal home care services for the recipient.

In Blakley and Jaffe's study (1999), almost all the caregivers reported having taken on

the role because of a lack of family alternatives: Other family members lived too far away or had passed away. Sometimes other family members were unwilling to help because of preexisting family dynamics, such as the care receiver's alcoholism or past abuse or neglect of these family members. Almost half of the caregivers identified dealing with frustration as a difficult task. A third found it difficult to deal with the care recipient's behaviour, for example, the behaviour of a man suffering from illness who does not wish to take baths and threatens to hit his wife when she suggests it, or of a 75-year-old widow who is finding it increasingly difficult to care for a son with disabilities who experiences intense mood swings. Many caregivers found having to make decisions on behalf of the care recipient a difficult task because of feelings of guilt and uncertainty.

3.22 HEALTH CARE RESTRUCTURING HAS PARTICULARLY HURT WOMEN

Armstrong has published an extensive body of work on the Canadian health care system restructuring, including home care and the impact on women. She documented the growing trend of placing the responsibility for health solely on the individual rather than the medical establishment and society. She pointed out how the language of the women's health movement has been co-opted by government to support withdrawal of intervention: ideas such as self-help, prevention, community settings, and reduction of physicians' autonomy, which were designed to give women more control over their health and reflect a more holistic approach to health, have instead been used to justify cutbacks to primary care and the offloading of health care work to mainly women unpaid caregivers. This withdrawal of intervention has resulted in a decline in the quality of care and in reductions in the choices available to and power of patients (Armstrong 1996).

A great deal of interest and research activity has occurred in Quebec about the effects on women of the shift from hospital to home and community care due to provincial health care reform in the 1990s. Research has come from a variety of sources, including grassroots organizations such as the Coalition féministe pour une transformation du système de santé et des services sociaux (1999), partnerships between grassroots organizations and academics (Côté et al. 1998), and agencies of the Quebec government (Conseil du statut de la femme 2000a). All came to the same conclusion: the shortening of hospital stays and the shift to home and community care has hurt women caregivers and care recipients because services are inadequate and underfunded and rely largely on an untrained, unpaid workforce of women who often do not have a choice about whether to provide care. These results are similar to those of studies done in every other province that focus on the effects of health care restructuring.

The groundbreaking research of Côté et al. (1998) was a partnership of five Quebec universities and a province-wide women's organization, l'Association féminine d'éducation et d'action sociale (AFÉAS). They met with female nurses, nursing assistants, orderlies, social workers, paid homemakers, and unpaid caregivers. Many of the caregivers had also been patients. Data were collected through focus groups in every region of Quebec and included a total of 32 participants from metropolitan centres (Montreal, Quebec City), small cities and towns (Hull, Gatineau, Aylmer, Chicoutimi,

Rimouski), and rural areas. In addition, 38 health and social service workers, most of whom were women, were interviewed individually.

In 1996, the Quebec government implemented a policy of health care budget cuts and the restructuring of health care services, which resulted in shorter hospital stays, more day surgery, the transfer of hospital staff to CLSCs (local community health and social service centres), heavier workloads for health workers, and a shift to community care and family responsibility for looking after sick relatives. During the course of the research, the authors noted that thousands of Quebec health care workers were displaced, dismissed, or deskilled (expected to perform skilled work for less pay). Shorter hospital stays affected women as patients (women were sent home earlier after giving birth and after surgery and treatments of all kinds), women as informal caregivers, and women as the majority of formal health care workers. The study found that informal caregivers must provide a growing and increasingly complex range of treatments. Côté et al. (1998) also noted that “More and more, women are expected to assume a heavier burden, and this has repercussions financially, in terms of their health and general well-being (stress, anxiety, insecurity, exhaustion) and in their personal, family and professional lives.” The authors reported that the restructuring of services and the transfer of care to the home have had a direct negative impact on the quality of care: home care and health staff were overworked and patients’ relatives are not always qualified to, or capable of, delivering the necessary care. The authors also concluded that the government’s policy of shifting care into the home entrenched the role of women as unpaid and underpaid domestic workers and rolled back some of the equality gains women have made. This study quotes extensively and effectively from women’s experiences with ambulatory care, making the situation vivid, as in this passage, for example: “After three days she was told she could go home.... She’s all alone. She couldn’t even dress or feed herself. I said: ‘Find her a convalescent home.’ The doctor thought that was frivolous” (caregiver, Montreal).

The participants in the Côté et al. (1998) study by and large agreed with some of the stated principles for the shift to community care, such as the humanization and de-medicalization of care (including greater patient autonomy and responsibility, faster convalescence at home, and the possibility of dying at home). The authors conclude, however, that these principles cannot be achieved through budget cuts, overworked health care staff, and lack of support for caregivers at home. The authors state that poverty, violence in the home, or lack of support can hinder caregivers’ ability to provide care to a sick relative. Sometimes, one’s children do not live in the same city. Many people cannot count on having a stable or caring support network, or one that is always available, “and even if this network exists, it can quickly become overwhelmed and overtaxed.” Appropriate care in the home cannot be assumed to be available (Côté et al. 1998). The authors found that care was being viewed by policy-makers from a financial, administrative, and bureaucratic perspective, that keeping the bottom line in check, rather than healing, was the primary goal. A Montreal hospital-based social worker interviewed by the authors made this observation: “Now, with the shift to ambulatory care, you’re not allowed to see a psychiatric patient more than 30 times. After that, you’re healed! They adopted the insurance model. If you’re in the private sector, insurance pays so much for psychological treatment, and so you’re given so much, and

no more. So, we're using a private model, and the message we're getting is we need to work as if we were in the private sector. If we were working in a private hospital, we'd have to show a profit. That's the message. We have to think profit." The authors reported that the needs of patients, informal caregivers, and paid health care workers were not being met under this model.

Aronson and Neysmith (2001) summarize some of the literature about the shift to care in the home as a result of hospital and institutional cuts as driven "by economic objectives and by political commitments to smaller government, individualism, and the transfer of work from paid to unpaid contexts..." Their article is based on their longitudinal study of 27 women home care recipients, ranging in age from 35 to 96, living in urban southern Ontario with a variety of chronic conditions and disabilities, receiving care for between 2 and 25 years. All the participants were white, eight were immigrants to Canada, and for five, English was not their first language. Their family and informal networks varied widely in geographical proximity, availability, and emotional closeness. The authors examined the effects of the introduction in 1996 of "managed competition" in home care in Ontario: 43 Community Care Access Centres (CCACs) distributed throughout the province monitor people's eligibility for services and arrange service through for-profit or nonprofit care providers. According to the authors, the CCACs experience rising demand and capped and uncertain budgets, and have rationed their services. The language of "managed competition" is market oriented and is focused on reducing public costs, enhancing efficiency, and increasing consumer choice.

Aronson and Neysmith (2001) pointed out that their sample of women with disabilities and women seniors receiving care did not find that managed competition gave them an increase in choice. Home care policies are played out in a cultural context in which old age and disability are disparaged, and those who experience it are not viewed as valuable human beings and participants in a democratic society. Care recipients wished to be viewed as citizens, not just as service users. The authors made the case for how the dominance of the health care perspective, which is increasingly market oriented, obscures the fact that these policies are creating or reinforcing the social exclusion of women with disabilities and older women from our society. The authors contended that care in the "community" obscures the fact that these women had a narrowing or nonexistent community, were isolated from others, and felt trapped in their homes. No transportation, long waiting times for assisted transit, and inaccessible toilets and other barriers at the destination meant that links with friends, associates, and community were difficult to maintain. Before the reforms, care recipients were allowed to have homemakers accompany them to local shops, to the bank, or on a walk, which sustained a sense of local connection, belonging, and independence. Those services, however, were deemed nonessential and were cut, leading to increasing isolation and exclusion of such care recipients from their communities. One said, "No one really knows...that I'm still alive..." Undependable home care service was also an issue. Because homemaking and personal care services were cut down to the bare minimum after the reforms, recipients felt apprehensive and ashamed of receiving visitors into their home because of its untidiness and their own unkempt appearance. Most recipients were now entitled to only one bath or shower per week, regardless of how their poor personal hygiene and appearance made

them feel. As well, some, who relied on meals being delivered to them, had little other food on hand to offer visitors, and may have had their nutrition jeopardized by the limited and repetitive menu. Personalized relationships between care providers and recipients is known to be a fundamental condition for good care; reforms meant that workers were rushed and unable to provide the social contact that recipients had valued. Changes and discontinuities in providers resulted from the shifting contractual arrangements between the CCACs and provider organizations. Recipients experienced a “succession of strangers” entering their homes and privacy; these caregivers required repeated and exhausting explanations of the care recipients’ particular needs and the organization of their homes. Certain tasks that homemakers used to do were now off limits, such as taking out the garbage. The CCAC’s hiring of private providers of meals also proved difficult for a recipient who was unable to open the meal containers. When she informed the CCAC of this, she was told nobody else had ever complained and nothing could be done.

As most of these women had very low income levels, “increasing consumer choice” was not something they experienced. Most of these women had no choice. The authors stated that the construction of care recipients as “consumers” or “customers” rests on false assumptions about their capacity to navigate the home care marketplace by themselves. Viewing them primarily as consumers rather than as citizens also individualizes the problem instead of emphasizing entitlement and focusing on offering a bridge to reintegration into mainstream society and participation in the community. If care recipients were dissatisfied with publicly provided services, attempts to get the services they needed were more often than not refused by the CCAC. Other care recipients were afraid to complain because they were dependent on the goodwill of case managers and care aides, a situation that left care recipients feeling powerless. In particular, a lesbian care recipient was reluctant to complain about poor service because her case manager disapproved of her sexual orientation, and the recipient felt she had to be careful.

The proportion of elderly and disabled women who had enough money to supplement diminished services by purchasing additional services privately were wary of advertising and of dealing with strangers and felt themselves to be in a vulnerable position. Case managers openly directed the study participants to turn to family members or referred them to commercial providers, assuming that everyone was in a position to pay. When involved and available, family members provided some social and practical support, but care recipients did not necessarily want to depend on tired family members who were dealing with their own problems. One care recipient said, “I’m just another burden...” to her daughter, who was also caring for a child with a disability. The study participants found all of Ontario’s health and social services less responsive than before the funding restrictions, and reported difficulties in accessing drugs and medical devices. The authors found that stereotypes about gender, old age, and frailty or disability interacted, leading home care providers and society at large to dismiss care recipients as being useless. Participants’ disempowerment and isolation left them few opportunities to develop a collective identity and internalized the contempt society and the home care system had for them, causing them to view themselves as burdensome and deficient. The authors noted that older and disabled women are rarely heard when the policies that affect them

are being made, which leads to the risk of their objectification and dehumanization.

Campbell, Bruhm, and Lilley (1998) also picked up on the language of “choice” that is used to justify the shift to home and community care. The authors stated that choice implies that there are viable options and that people select the option that benefits them most. According to the authors, women do not necessarily make a “choice” to decrease or discontinue their paid work in order to care for other people; often women have no option. They are pressured to take on this role, and often formal home care services do not provide the hours of care that recipients need. Women care recipients have told researchers that that they “do not wish to be a burden” on their families, and yet, because of inflexible, inadequate services often provided by undertrained or untrained and underpaid staff, and high turnover, they must “choose” to rely on family members. Recipients and families also do not have enough choice about who is an appropriate home care worker in terms of meeting the recipient’s needs (Campbell, Bruhm, and Lilley 1998).

Aronson and Sindling (2000), using the same longitudinal data as Aronson and Neysmith (2001), focused on the implications for case management. They described the awkward position in which case managers were placed: once advocates for home care recipients, now case managers are rationers of scarce services that in many cases do not meet the needs of and even endangered the health of recipients. For example, a home care recipient was told nothing could be done when she requested that her nails be cut more often than the standard twice a month because her involuntary movements caused her to scratch herself. Some recipients began to view their case managers with distrust, as people who cut back on services even if the care recipient’s medical need had not changed. One case manager asked a care recipient who had reached the upper limits of her allotted hours to get her building superintendent to administer her eyedrops. Care recipients generally expressed low spirits and a sense of hopelessness and diminishment, and had the most positive appraisals for case managers who bent the rules and went the extra mile — that is, followed their conscience rather than the policy. The article also contained feedback from case managers, who felt demoralized, powerless, rushed, frustrated, and tense, and some of whom were defensive and tried to blame the care recipients for their condition.

In a study of the support needs of rural Nova Scotian caregivers, Campbell, Bruhm, and Lilley (1998) found that some caregivers have felt abandoned by government. It may be that even if some governments have invested or reinvested in primary health care or in community care, these reinvestments have not been sufficient to meet the growing demand for care. As technology accelerates, life is prolonged both for older people and for children with disabilities, who may not have lived 50 years ago. In addition to the greater number of people who need care, the number of caregivers has diminished due to smaller family sizes and the fact that families are more spread out geographically (Campbell, Bruhm, and Lilley 1998).

Underfunding and insufficient services also were a theme in a gender-sensitive study conducted in Manitoba and Newfoundland. Morris, Robinson, and Simpson (1999) conducted a study of 51 male and female care recipients, unpaid caregivers, and paid

home care workers in Winnipeg, Manitoba, and St. John's, Newfoundland. Sixteen of the 51 participants were of British ethnic or cultural ancestry, and the remaining 35 identified themselves as of Ukrainian, Aboriginal, Irish, French, Jewish, Polish, Filipino, Dutch, German, or of mixed ethnic or cultural background. The authors supplemented the data with interviews with provincial and federal policy-makers, regional health authorities, managers of home care agencies, academic experts, and representatives of organizations such as Aboriginal Nurses of Canada and the Canadian Home Care Association. Morris, Robinson, and Simpson (1999) found the following:

- Care recipients suffered from inadequately funded home care, which led to barriers in access to subsidized care due to tight eligibility requirements, inadequate hours of home care services being assessed, and limits on hours of care and type of care. Underfunding also had an impact on whether quality-control standards were ignored: some paid home care workers had no training, not even the required first-aid certificate. Underfunding resulted in some care recipients receiving fewer hours of care than their doctors recommended. It was particularly difficult for older women in Newfoundland to obtain publicly funded care. Participants reported that women were sometimes inappropriately assessed for fewer hours of care than men because of the greater expectation on the part of case managers that older women, women who were ill, and women with disabilities could take better care of themselves than men. This meant more work for primarily female unpaid caregivers.
- Many who were satisfied with care had low expectations and were just grateful that anybody paid attention to them at all. The older cohort of women, who grew up in the days of no public health care and no public social services, may have less of a sense of entitlement than the generations who will be needing home care in the future.
- Regional and provincial variations in funding left caregivers and care recipients with unequal access to publicly funded home care. Eligibility for service and maximum number of hours of paid care, as well as whether or how much the recipient is required to pay, vary by jurisdiction. Access to private purchase of home care depends on income. Older women and women with disabilities tend to have very low incomes and are not able to purchase services.
- Underfunding of home and community care was compounded by insufficient support from other government programs; inadequate income support programs for older women and women with disabilities, the two largest user groups of publicly funded home care, made these groups extremely vulnerable to poverty, which has health and social impacts beyond not being able to cope with the private costs associated with care in the home.

- Caregivers were not always aware of respite care services available. The female gender role could lead to underuse of services even if caregivers were aware of them, as female caregivers might feel guilty about taking time for themselves. Sometimes the fees for these services put them out of the reach of the caregiver, which could particularly be true for female caregivers because a statistical gap exists between women's and men's incomes, leaving women in a poorer economic position to purchase services.
- When services are underfunded, little outreach is done because the last thing overloaded publicly funded service providers need is more clients. This could be a factor in the continuing inaction on making services culturally sensitive, which leads to the underuse of publicly funded home care services by Aboriginal peoples and some ethnic, racial, and linguistic minority communities. This in turn places particular pressure on women from these communities to provide home care on an unpaid basis.
- Caregivers and recipients reported a lack of control, information, communication, and coordination because underfunded systems did not function as efficiently as they could.

Some of these findings were confirmed by other gender-sensitive studies:

- Respite care is inadequate and difficult to access (Campbell, Bruhm, and Lilley 1998).
- Resources are limited (Hawranik and Strain 2000).
- It is difficult to find out about and obtain services (Hawranik and Strain 2000).

Almost three-quarters of a million community-dwelling seniors received care from family and friends for long-term health problems, compared with 186,500 seniors living in health care-related institutions (Keating et al. 1999). It can probably be said that the provision of unpaid care in the community prevents institutionalization and further costs to government arising from it, but offloads these costs onto primarily female caregivers and care recipients.

The disconnection between the stated goals of policy-makers and the experience of caregivers and care recipients has led many of the authors whose studies were reviewed for this paper to conclude that cost reduction, rather than quality of care or equality goals, is at the root of health care restructuring and that this has a particularly deep and negative impact on women as caregivers and care recipients. The economic value of the labour provided by caregivers is sometimes obliquely referred to by policy-makers, but they do not recognize this labour concretely or in a meaningful way: any aid to caregivers tends to be means tested, and what little is available is provided because the caregivers in question are very poor, rather than because their work is valued. Campbell, Bruhm, and Lilley (1998) said this: "By reducing the need for costly institutional care through free labour, caregivers subsidize health reform and contribute substantially to the economy."

3.23 CAREGIVERS, WHO ARE PREDOMINANTLY WOMEN, AND CARE RECIPIENTS, WHO ARE PREDOMINANTLY OLDER WOMEN AND WOMEN WITH DISABILITIES,

ARE LEFT OUT OF THE POLICY-MAKING PROCESS

A number of studies mentioned that many caregivers believe that governments talk about being “partners” in care, but the caregivers are not listened to (Campbell, Bruhm, and Lilley 1998; Côté et al. 1998; Hawranik and Strain 2000).

In a study of frail elderly people receiving care, unpaid family caregivers, and paid home care providers, Aronson and Neysmith (1997) pointed out that policy decisions about the design, operation, and implementation of long-term care programs have not taken into account the views of those most affected, the frail elderly themselves. Political rhetoric about consumer “choice” has served to obscure the “oppressive realities of having to rely on family members to accept meagre public services.” Policy discussions and most home care research ignore those in Canadian society who “do not fit in with the homogeneous picture of “family care,” such as people without children, same-sex couples, and families that do not fit the description of a traditional, North American, nuclear family (Aronson and Neysmith 1997).

Harlton, Keating, and Fast (1998) held seven focus groups with different stakeholders in eldercare: elders, family members, friends and neighbours, volunteers, direct service providers, local and provincial policy-makers, and federal policy-makers. These researchers found a marked difference between the views of elders and policy-makers as to who should provide eldercare services. Policy-makers believed that the best care is from unpaid sources close to the older adult. Seniors, on the other hand, said they did not want to “be a burden” on their families, and that using public or other paid services allowed them to remain in control. The one gender-sensitive result reported in this study was the gendered nature of life skills being a determinant of need. The authors cited research that shows that among persons with advanced cancer, half of the help received by married men is a result of gender role responsibilities rather than a result of functional disability. That is, many older men may be physically capable of doing the work, but are inexperienced and perhaps do not wish to learn how to cook, shop for groceries, and so on.

In addition to including care recipients’ and caregivers’ gendered perspectives as the basis for policy-making, it is also important to consider the perspective of paid home care workers, over 90% of whom are women (Morris, Robinson, and Simpson 1999). One issue that arose in the literature was the pitting of unions and people with disabilities against each other over the issue of control over whom to hire as a home care worker. People with disabilities have been advocating for greater control over whom to hire, including hiring family members with public monies, as they are concerned about feeling comfortable with the worker, continuity of care, and the bond between worker and care recipient. From a gender perspective, there is a shortage of male workers, and often female workers are assigned to male care recipients who might prefer a male worker. If care recipients hired whom they pleased, they might have a better chance of finding a suitable home care worker. Women care recipients may be concerned about their personal safety with home care workers and may feel less vulnerable if able to choose the worker themselves. If care recipients and their families are obligated to hire workers, however, going through the advertising, recruitment, interviewing, and hiring process

may prove to be an additional burden. Issues about screening, accountability, and tax and other employer-related obligations may also turn into a nightmare for vulnerable recipients and their families. On the other hand, unions are concerned about wages, working conditions, representation, and mechanisms to redress wrongs such as abuse. As conditions can already be very bad particularly for home support workers, the vast majority of whom are women, unions do not want to see more power over whom to hire, wages, and working conditions go to individual care recipients (Morris, Robinson, and Simpson 1999). Having representatives from all stakeholder groups — care recipients, unpaid caregivers, and paid home care workers — at the policy-making table, the gender of the representatives reflecting their actual proportion within those groups, may facilitate solutions that meet the needs of these three predominantly female groups.

3.24 OVERVIEWS AND ANALYSES

Many factors influence the caregiving experience: family dynamics and history, values and beliefs about the role of the family and the formal care system in providing assistance, financial circumstances, the personality of the caregiver and the care recipient, and the nature of the caregiving network (Hawranik and Strain 2000).

Why do women form the majority of caregivers? The consensus is that women are socialized and viewed by society as “natural” caregivers and feel pressure to do this work for free (or rather, at their own expense) (Armstrong 1996; Aronson and Neysmith 1997; Campbell, Bruhm, and Lilley 1998; Hooyman and Gonyea 1995; Kaden and McDaniel 1990; Morris, Robinson, and Simpson 1999; Roehrer Institute 2000b; Tremblay et al. 1998). Morris, Robinson, and Simpson (1999) confirmed the findings of other studies that showed that women family members were expected to fill in for inadequate home care services without pay and at great personal expense in terms of their own health, income, benefits, career development, and pension accumulation, whereas men were not under similar pressure to do so.

Although caregiving remains a female gender role, many changes have occurred in the last century that have shifted the pressures and expectations on women. Armstrong and Kits (2001) produced an overview of the history of caregiving in the 20th century and drew the following conclusions:

- The century was characterized by the entry of married women into the paid labour force; smaller, more mobile families, reflecting access to birth control; rising participation of women in the labour force; and increasing rates of divorce. These changes had an impact on women’s availability to provide unpaid care.
- Formal health care services expanded, progressed, and became publicly funded, which, along with improved nutrition, housing, income, and sanitary and employment conditions, ensured that more people with a disability survived and more people lived into old age. These changes have meant that more people need care now than was the case in the past.
- New chronic diseases appeared, such as HIV/AIDS and Alzheimer’s, as some acute infectious diseases disappeared. These changes have led to an increase in demand for

- long-term care.
- New technologies and a move to cost cutting in the later part of the century resulted in deinstitutionalization and an unprecedented number of people being cared for in the home, in unprecedented ways. Lay people are now expected to develop a certain medical knowledge and learn how to administer treatments.
 - Although more women than ever are in the paid labour force and families are smaller and therefore have fewer human resources on which to rely, care demands have grown substantially in both number and complexity.
 - A strong and sweeping government orientation toward cutbacks — reducing or eliminating supports such as public housing, transportation, and employment protections — increased inequality in access to necessary services and supports. Throughout these massive changes, the one thing that remained constant was women's responsibility for unpaid caregiving.
 - The study made the point that unpaid caregiving can be a rewarding experience for those who choose it, but it becomes a threat to physical and mental health and personal relationships when it is not willingly undertaken and is done without adequate supports and relief.

The finding that women care recipients consistently receive fewer hours of care from informal caregivers is a concern (Keating et al. 1999). It could be that women seniors are actually more willing and able to care for themselves and perform their own household tasks. Since health problems are certainly not confined to men, however, it is more likely that the needs of women recipients of care are going unmet, perhaps because it is assumed by care assessment officials and unpaid caregivers that women recipients can take better care of themselves than their male counterparts. There may even be an element of denial around the need to care for mothers who have developed functional limitations because formerly these women were competent and capable and performed all these tasks on their own and for their children. Home care policies and systems must become gender sensitive to ensure that women with functional limitations are getting the care they need; that expectations, stereotypes, and familiarity with female gender roles are not interfering with women's ability to access care; and that gender bias is not being entrenched.

Sometimes the assumption might be made that the care recipient is not a participant in the labour force, and thus much research does not take into account the effects of inadequate care on the paid work of care recipients. A number of women and men with disabilities require care support in order to fulfill the responsibilities of their paid work. No gender analysis has been done in this area.

The possibly conflicting rights and needs of the caregiver and the care receiver, as well as neglect of the care receiver, are important issues. As outlined in previous sections, caregivers may suffer from clinical depression, neglect their own needs, and feel completely overwhelmed. On the other hand, care recipients are extremely vulnerable, and withholding from them the necessities of life amounts to a human rights abuse. It is important to look at the systemic factors and lack of support that can lead to some situations of neglect. So far, the literature on abuse tends to consider the issue of elder neglect as one of individual responsibility and a criminal matter, rather than as a wider social responsibility and a matter of inadequate services.

There has long been an interest in women's caregiving role as mothers. On the federal policy level, this dates back to the 1970 Royal Commission on the Status of Women, which documented the conflict and stress between women's paid work and women's unpaid work in the home and recommended a national child care program. Over the years, a House of Commons standing committee and another inquiry — the Royal Commission on Equality in Employment — also examined this aspect of caregiving in detail, along with much work at the grassroots level that centred on pensions for homemakers and counting women's unpaid work in the census. In recent years, more of a focus has been put on women's caregiving of people with functional limitations, probably because of the aging of the population and the devolution of health care from hospitals to the community (that is, to women). Women's caregiving roles, however, both paid and unpaid, should be viewed as a whole.

McGregor (1995) edited the conference proceedings of a symposium about women as family caregivers organized by the National Council of Women in Canada, l'Association féminine d'éducation et d'action sociale, Mothers Are Women, and the Canadian Home Economics Association. The speakers and panel participants gave overviews of women's domestic labour and its value to the economy. The conference took a holistic approach, which included women as caregivers of non-disabled children, as well as of people with functional limitations due to illness, old age, or disability.

If these caregiving issues (child care versus care for people with functional limitations, underpaid versus unpaid care) continue to be examined as if they were not related to one another, no clear picture will emerge as to why it is women who do this kind of work, how this type of work causes stress and role conflict, and how support measures to deal with the overall gender roles in which women are placed are inadequate, in terms of both helping them cope with these roles in the short term and seeking a just and equitable solution to the problem of socializing women to be a stressed, unhealthy, unpaid labour force.

Although this paper is not meant to cover the situation of paid home care workers (that research is being done by Human Resources Development Canada), Aronson and Neysmith (1997), Côté et al. (1998), and Morris, Robinson, and Simpson (1999) made the case for how interrelated paid home care work, unpaid caregiving, and receiving care are. First, the underfunding of home care, which resulted in low wages, irregular hours, inadequate training, and high turnover of staff, translated into poorer quality care for recipients, such as lack of continuity of care, staff shortages, and waiting lists. This in

turn meant that women as informal caregivers were expected to fill these gaps in formal care. Second, all three stakeholder groups —paid home care workers, unpaid caregivers, and care receivers — were dominated by women who are all overwhelmingly affected by the socioeconomic impact of gender inequality (particularly in relation to the underpaid and unpaid caregiving role), which contributes to poverty in old age for unattached women and subsequent reliance on public home care systems.

One work that looked primarily at the systemic equality issues in caregiving was Hooyman and Gonyea’s classic U.S. work, *Feminist Perspectives on Family Care: Policies for Gender Justice* (1995). This book gave an overview of the history of feminist politicization of unpaid care, and attempted to change the discourse about home and community care from being an issue of individual maladaptation that could be fixed by tinkering with policy to one of structural inequality that required a transformation of policy and society. The authors pointed out that even studies that recognize caregiving as a women’s issue tend to highlight subjective stress and caregiver burden, and thus result in recommendations involving coping methods, such as education, counseling and social support, and incremental changes in service delivery models. The authors stated that “the overriding issue is not how to relieve individual stress but how to organize society to achieve gender justice so that care for dependent populations across the life span is more equitable and humane for both those who give and those who receive care.... From a policy perspective, feminists are now questioning how services for adults with disabilities can be offered in ways that do not rely primarily on women to do either the unpaid or underpaid work of caring” (1995: 20).

Hooyman and Gonyea (1995) detailed data on demographic shifts; the changing economy and workforce; changing health needs and services; the social, political, and historical context of caregiving; the gendered nature of care; and the consequences of caring with a focus on caregiver burden. They provided an analysis of U.S. long-term care policies and family-related benefits in the workplace, and made a range of recommendations concerning economic supports, social services and supports, policies for a more family-responsive workplace, and health care reform. The authors also advocated the formation of a national caregiver coalition that would engage in political advocacy for gender justice in caregiving and recognize that race, ethnicity, and income intersect with gender, rather than rely on associations whose mandates are primarily oriented toward specific diseases and that do not necessarily undertake any gender or social justice analysis.

4. RESEARCH GAPS

This section deals with two major types of research gaps:

- the gap in home and community care literature in general in terms of producing research and analysis that is gender sensitive
- the research gaps within the gender-sensitive home and community care literature

4.1 GENDER GAPS IN HOME AND COMMUNITY CARE RESEARCH

A huge amount of Canadian and international literature on home and community care exists, but only a small fraction of it contains any gender analysis. For example, “Key Issues in Home Care: An Analysis of Canadian Home Care Association Resource Materials,” a 1998 report prepared for Health Canada by the Canadian Home Care Association, contains no mention of gender in the section on the role of family and volunteer caregivers, nor in the sections on clients or paid workers. The demographics section contains one mention of women, stating that the number of family caregivers is declining as more women enter the workforce.

Some studies mention in passing that the majority of caregivers are women or, less often, that the majority of care recipients are women, but these studies include no gender analysis of their data, perhaps due to an assumption that caregivers have a uniform experience and that gender does not matter.

Some studies that do take gender into account, in both data collection and analysis, fall short in terms of passing the tests of gender-sensitive research: these studies may suffer from a lack of familiarity with previous gender-sensitive work and perspectives that might have informed the research. For example, an Oregon State University study examined gender differences among caregivers of spouses suffering from Alzheimer’s (AD) and Parkinson’s disease (PD) (Hooker et al. 2000). The authors noted that most of the literature reports that caregivers who are wives generally fare worse than caregivers who are husbands. The authors postulated that gender differences would not be as strong among caregivers of cognitively intact spouses (such as caregivers of people with PD) because caring for cognitively intact spouses may involve less severe reciprocity losses. Gender differences in coping strategies within each group were also examined in this study. The authors found that wives who cared for husbands with AD reported significantly worse mental health outcomes than husbands who cared for wives with AD, but no differences were found between wives and husbands who cared for spouses with PD. Caregiving wives of spouses with AD were less likely than their male counterparts to use problem-focused coping strategies. The authors concluded that the loss of reciprocity in marital relationships may affect women more negatively than men. Had the authors taken into account previous research that shows a marked difference between caregiving women and men in the volume and type of duties they perform, and that constant care may be necessary for someone living with AD, they might have examined another variable in their study — one that might have had a significant effect on the results and the interpretation of their data. This is an example of an issue discussed in the introduction to this paper: Gender-based analysis is not just about counting women and men or factoring in sex or gender as a variable. Women who are providing more hours of care, are performing more difficult care, and are at greater risk of violence and exhaustion are not necessarily in any shape to engage in “problem-focused coping strategies.” Gender-based analysis must include becoming familiar with the findings of gender-based research, which can then guide a researcher or analyst toward asking the right questions and taking into account, when conducting or interpreting research, the socioeconomic differences and different life experiences of women and men.

Disease-specific associations (such as the Canadian Cancer Society and the Alzheimer’s Society) generally have information about how to obtain home care services. The

mandate of such organizations, however, does not include conducting gender-based analyses of home and community care. As well, broad coalitions, such as the Canadian Home Care Association, have little in the way of gender-specific materials. Their focus is home and community care in general, not women's equality issues within home and community care. Organizations such as Aboriginal Nurses of Canada, Pauktuutit Inuit Women's Association of Canada, and others produce a large number of useful documents that address priority health issues, but these organizations have nothing specifically on home and community care. Health centres such as Women's Health in Women's Hands (WHWH), which is a team of health professionals who specialize in working from a feminist and anti-racist perspective with women from the Caribbean, Africa, Latin America, and South Asia, provide frontline services and are not necessarily in a position to provide gender-sensitive research on home and community care that would take into account diversity among women. Although WHWH does offer some publications, they tend to be about issues of priority to their Toronto clients. Among these publications are booklets for Black women living in Canada about becoming pregnant and publications about female genital mutilation. Most of the gender-sensitive home and community care studies are performed by the Centres of Excellence for Women's Health and by academics. There is more U.S. than Canadian academic literature, although the Canadian literature tends to be of high quality and relevance.

Given that women and men have different experiences of care, both as givers and receivers of care, and sometimes as both at once, a gender-based analysis can show where the problem areas are. Programs, policies, and legislation should not be incorporating — as a part of their very foundation and structure — unequal social roles that have serious economic consequences. The fact that women and men have very unequal burdens as caregivers is a matter of public health and economic concern. The fact that women care recipients may not be assessed for as many hours of care as men because of sexist stereotypes is a matter of public policy concern. If gender-specific data are not collected, the problems go unnoticed.

It is important also to apply a gender analysis throughout a piece of research, and to take into account preexisting research in the area that might give clues as to what the gender differences are and what to look for. A study that documents that women experience greater caregiver burden than men, but that does not collect and disaggregate data on such variables as how many hours of care per week are given, the impact of caregiving on paid work, and so on, might simply conclude that women just complain more than men. Collecting the other data will show that women, on average, actually do more caregiving work and that it has a greater impact on the paid work, health, and lives of caregiving women than it does on those of their male counterparts.

Clearly, although there is a growing body of literature about gender and home and community care, the majority of the home care literature still does not take gender into account. This has implications for the sensitization of and outreach to researchers and policy-makers about the importance and value of gender-based analysis.

4.2 GAPS WITHIN THE GENDER-SENSITIVE HOME AND COMMUNITY CARE LITERATURE

4.2.1 Aboriginal home care

Significant gaps exist within the gender-sensitive literature on home and community care. One such gap is data on Aboriginal women and men and home care. In general, the literature on Aboriginal home care points to different health issues, cultural expectations, and bureaucratic structures facing Aboriginal peoples. The literature on Aboriginal women's health and access to health care documents gender factors, but perhaps because of the sheer volume of threats to Aboriginal women's health and access to health care (Dion Stout, Kipling, and Stout 2001), home and community care has not been a focus.

4.2.2 Immigrant, refugee, and visible minority communities

There is not enough Canadian-based gendered literature on immigrant, refugee, and visible minority populations and home care. Some of the studies that have taken these groups into account did not perform an analysis based on race or ethnicity, and some studies lumped together different groups (such as Haitian and Italian) without analyzing whether the experiences of these groups were different. Community-based organizations currently do not have the financial resources to undertake research of this nature.

Gender-sensitive home and community care research for specific communities would be useful in shaping policy responses. For example, a number of immigrant and refugee women from certain countries of origin may have undergone female genital mutilation. This and cultural barriers may have an impact on how comfortable women feel in accepting intimate personal care that would expose private areas of the body, and may have implications for training and sensitivity of home care workers.

4.2.3 Minority sexual orientations

Better statistical information on lesbians, gay men, and bisexuals involved in giving or receiving care would be a useful complement to the existing small-scale qualitative research in this area. The qualitative research shows that some lesbians in need of care may have fewer family resources on which to draw because their family of origin may reject them or have an uneasy relationship with them. According to Aronson (1998), lesbians sometimes face hostility and discrimination from health care service providers, and because of this, some lesbians have the added responsibility of caring for other lesbian friends, as well as partners and family members.

4.2.4 People with disabilities

More and more accessible gendered statistical profiles are available about caregiving of seniors with functional limitations than about caregiving of people with disabilities in general. The focus on seniors is increasing and the focus on people with disabilities is diminishing. A small example is that Statistics Canada's 1995 edition of *Women in Canada: A Statistical Report* contained a chapter on women with disabilities, whereas women with disabilities were not discussed in the subsequent edition, *Women in Canada 2000: A Gender-Based Statistical Report*. The focus on seniors rather than adults under age 65 with disabilities may reflect the perceived political power and relevance of these two groups.

4.2.5 Human rights perspective

Only a minority of the gender-sensitive research is conducted by or from the perspective of people with disabilities and frail seniors as full human beings who have the right to participate in a democratic society and who are potential agents for change. The view that care recipients are objects is even more prevalent in the non-gender-sensitive literature, but it is also present in some of the gender-sensitive literature.

4.2.6 Violence, health, and safety

Côté et al. (1998) and Morris, Robinson, and Simpson (1999) discussed the vulnerability of care recipients to violence and personal safety risks from being handled by untrained caregivers. These researchers also documented abusive family dynamics that might have an impact on care. Women caregivers may be at greater risk of injury from violence by abusive or mentally ill care recipients, or from activities such as lifting heavy care recipients from a bed to a chair, and so on. More research is needed in this area.

Some documentation exists about the financial abuse of seniors, but little about the financial abuse specifically of all kinds of home care recipients by paid and unpaid caregivers.

4.2.7 Financial impacts of caregiving

Many studies point to the interference of caregiving duties with paid work, particularly for women (Blakley and Jaffe 1999; Campbell, Bruhm, and Lilley 1998; Côté et al. 1998; Gignac, Kelloway, and Gottlieb 1996; Keating et al. 1999; Morris, Robinson, and Simpson 1999). However, the average life-long financial impact on individual women and men of care-related absenteeism, reduced work hours, or unpaid leave has not been measured. Some work has been done in the area of economic impacts and financial compensation of caregivers of seniors (Fast, Eales, and Keating 2001; Keefe and Fancey 1998), and work is in progress at the B.C. and Maritime Centres of Excellence for Women's Health on the gendered socioeconomic costs of palliative caregiving in the home. None of these studies take into account caregivers of all persons with functional limitations.

Not only is the research about the gendered financial impacts of home care preliminary and limited in scope, but also employers do not have a grasp of how significant this problem is within their organizations and of how much the hidden costs of caregiving are absorbed by employers in sick leave, vacation time (which leaves employees more tired from caregiving), and absenteeism. This area of research would be interesting and its findings useful.

4.2.8 Financial compensation programs

Armstrong and Kits (2001) identified a research gap in the area of the impact of direct financial compensation programs on caregivers and recipients. Keefe and Fancey (1997) studied Nova Scotia caregivers' experience of limited pay, but other research would be useful, such as undertaking an up-to-date analysis comparing home and community care and caregiver support mechanisms in Canada with those in selected industrialized countries. Keefe and Fancey (1998) briefly outlined programs in Austria, Canada, France, Germany, Ireland, Britain, the Netherlands, Norway, Sweden, and the United States, but did not include a gender analysis of the socioeconomic effects of these programs.

4.2.9 Legal status of caregivers

Unpaid caregivers do not qualify for workers' compensation when injured while providing care, and they neither fall under labour standards legislation nor have vacation leave or benefits. The issue of professional liability for inappropriate care is also unclear. With home care freezes in some provinces where demand is increasing, inappropriate care may result from the offloading of tasks onto untrained caregivers. This may expose provincial governments and regional health authorities to litigation. Some groups are questioning whether the equality provisions of the *Canadian Charter of Rights and Freedoms* would apply, given the gendered nature of caregiving.

4.2.10 Health effects of being coerced to care

A number of studies have been done about the health impacts of caregiving on women and men, but one interesting variable that has not yet been included is whether health impacts differ between those who choose caregiving and those who are thrust into it because of a lack of alternatives. Research might even uncover health benefits to fully supported caregiving that is done by choice, in which the caregiver and recipient get as much outside support as they need and the caregiving situation is the preferred option for both parties.

4.2.11 Men who give care

Although some studies address the obligation to provide caregiving, particularly among women who are fulfilling an expected female gender role, it might be useful to take a closer look at men who take on this female gender role of caregiving to see what differences exist between the few men who provide many hours of care and the many men who provide few. Do these groups differ in terms of psychological measures, socialization experiences, and socioeconomic factors? Answering such questions may

help us develop an understanding of how caregiving responsibilities can be better shared between the sexes.

4.2.12 Regional data

Regional gaps exist in the research. No published gender-sensitive home and community care studies are based on data collected in Alberta, Prince Edward Island, Yukon, Northwest Territories, or Nunavut. Although research is not restricted to the province in which a Health Canada–funded Centre of Excellence for Women’s Health is located and cross-centre research is undertaken, the presence of such a centre in a province has made an enormous difference in terms of whether research about gender and home care has been conducted in that province and region.

4.2.13 Broader and action-oriented approaches

Although many gender-sensitive studies recognize the systemic factors pushing more women into care, these studies tend to recommend measures that would better help women cope with their caregiving role, such as making respite care more available and accessible, rather than developing strategies that women and activists can adopt to challenge the gendered nature of the caregiving role. As there have been and continue to be activist campaigns that recognize, value, and challenge women’s role in caregiving, research focusing on the progress of these sometimes isolated movements, their successes, and setbacks, and on potential strategies for obtaining justice for caregivers, would be invaluable.

Action-oriented research can include the feasibility of using human rights instruments and bodies to challenge current home care policies and practices on the basis that they discriminate on the basis of gender, age, and disability, or on the grounds that accessible, comprehensive care is lacking.

Part of the problem is documenting needs and espousing values of quality care and support within a climate of fiscal restraint and industrial models of care. Advocates of better care need information about how to effectively communicate existing research and needs to decision-makers so that change is possible.

Another gap in action-oriented research is how to raise public awareness about the value of caregiving and how to build coordinated public support for policy measures that would alleviate the burden on caregivers.

Broader approaches would also look at policies relevant to supporting caregivers and care recipients beyond immediate service issues. These broader approaches include housing, employment, work and family, and income-support policies.

4.2.14 Alternative models of caregiving

Most studies about unpaid caregiving concentrate on close relatives as caregivers. Aronson (1998) discussed a community network of friends of a lesbian with breast cancer who between them provided unpaid care. Little research has been done on alternative models of care, the role of friends, and the legal and social status of friends when trying to arrange for formal care when hospitals and other institutions prefer to deal exclusively

with close family members. Other possible models of care involve two couples sharing the care of a child with disabilities, pastoral care provided by churches and other faith communities, networks of informal caregivers in co-op housing, and so on. Although there is much discussion of “community care,” very little of this care actually involves the community as a whole.

Other issues in alternative models of caregiving include reciprocity: what has the care recipient provided to the community, and what can she continue to provide? In Aboriginal traditions, the role of the elder is very important. The elder is seen as a wise and valuable member of the community. Alternative models of caregiving can explore not only the physical care needs of the recipient, but also how the recipient can continue to be recognized as a valuable member of her community.

4.2.15 Best models and best practices

The literature about gender and home care has focused on the problems and on recommendations for solutions. It has not, generally speaking, documented best practices and models. Perhaps no models of home care exist that are constructed with a gender analysis and commitment to gender equality goals and that do not disadvantage women as care recipients, unpaid caregivers, or paid home care workers. Documentation of a successful model that takes gender equality into account would be a useful contribution to the literature.

4.2.16 Holistic views of caregivers and care recipients

The research tends to dichotomize caregivers and care recipients.¹³ One area that requires research is that of the situation of caregivers who are also in need of care, such as women over age 65 who tend to be caregivers to spouses or to adult offspring with disabilities, and women with disabilities in general who may be both caring for children and in need of support for functional limitations at the same time. Another area of interest is women and men who need care in order to better perform their own paid or unpaid work, for example, persons with disabilities who have paid employment and caregiving responsibilities for children or other persons. If women have less access to care than men, does this in turn have a further financial impact on them in terms of their ability to make a living?

4.2.17 Caregiving as a whole

Other useful pursuits might be to broaden the focus of research from primarily eldercare to care of other persons with functional limitations, that is, to recognize the caregiver role

¹³ There are rare exceptions to this, such as the research of Côté et al. (1998), which clearly showed that many caregivers — from women discharged early from hospital after childbirth or illness to women seniors — are also in need of care.

as a whole, including the care of children and spouses without functional limitations and the care to community members.

5. CONCLUSION: MAJOR THEMES AND POLICY IMPLICATIONS

5.1 MAJOR THEMES

The studies took place in different locations around Canada and the world, yet the results were often similar and complementary. The following major themes emerged from the literature:

- Women are on the front lines of caregiving and receiving care, and home and community care policies and practices affect them in different ways than men.
- Compared with male caregivers, female caregivers put in more hours of care on average, perform different (more personal and demanding) types of care, travel farther and more often to provide unpaid care, and feel under a greater obligation to provide unpaid care.
- Caregiving has a greater overall impact on women, compared with men, in terms of having to rearrange their lives, the impact on their health, and the personal long-term financial cost.
- Caregiving is more stressful for women than men, largely because of the demands of women's multiple caregiving roles (caring for older or disabled adults, caring for children, caring for several people with functional limitations), and because services across the country are inadequate to fully meet the needs of both caregivers and care recipients.
- Caregiving responsibilities are a significant contributing factor to economic inequality between women and men.
- Women, as the majority of caregivers and care recipients, have been hurt by health care restructuring, which has both increased the burden of unpaid care and diminished available services. Health care restructuring interacts with other cutbacks and with reforms to income support programs, other social services, and special needs education, leaving low-income caregivers and care recipients with fewer choices. Many caregivers are dissatisfied with the amount of support provided by government and community.
- Although the language of the shift to home and community care involves increasing "choices" for "consumers," very little choice is involved in home care for either caregivers or care recipients, particularly when they are women. As a caregiver in one study said, "I have not chosen to become a caregiver. I've been stuck with the job because no one else wants it" (Blakley and Jaffe 1999).
- Women's unpaid caregiving is invisible. It is confined to the home and provided by women who are largely isolated, tired, and in a poor position to organize for change as a group.

- Women recipients of care receive fewer hours of care than men recipients (Keating et al. 1999), a reality that may reflect gendered stereotyping and the view that women are better able to cope on their own than men. As a result, women are at greater risk of having their needs unmet.
- Seniors and people with disabilities, especially women, may be both caregivers and in need of care themselves.
- Some groups — such as women in immigrant communities facing cultural and sometimes linguistic barriers to publicly funded care, women in visible and ethnic minority communities experiencing racism in health services, and women in Aboriginal communities dealing with poor programming, cultural barriers, and jurisdictional issues, as well as lesbians and gay men facing stigmatization in their access to health care and provision of unpaid care — are facing harsher challenges than others.
- The value of caregiving work is not adequately recognized by government or society. The provision of unpaid care in the community by women prevents institutionalization of people who need care and saves governments money, but does so at a cost to women. Canada as a society must look at options to reduce the social and economic inequalities that are exacerbated by women's role as unpaid caregivers.

Although the majority of gender-sensitive studies on home and community care concentrate on the effects on women, the gender imbalance in paid and unpaid caregiving may also be detrimental to men as care recipients. There are not enough male home care workers to do personal care for elderly men (Campbell, Bruhm, and Lilley 1998). This results in uncomfortable dynamics, such as daughters having to change their fathers' incontinence garments (Côté et al. 1998).

5.2 POLICY IMPLICATIONS AND RECOMMENDATIONS FROM THE RESEARCH

What would good care look like? What kinds of care would be good for women and men, for families, for communities, and for the country? How can we support caring relationships without coercing women into providing unpaid care?

Numerous policy options were identified in the literature. Some were geared toward improving services; others dealt with more drastic policy changes aimed at valuing the caregiving role and the experiences of recipients; others were broader policy changes aimed at transforming the root causes of gender inequality in caregiving and in home and community care. It can be argued that some of the policy recommendations fit under multiple categories. For example, recognizing caregivers and their needs in the development of policy would be a measure to value the caregiving role, but would probably also lead to an improvement in services for caregivers and recipients.

Not all of these policy recommendations are gender specific. For example, some gender-sensitive literature on home and community care calls for better and more accessible respite care, not necessarily respite care programs specifically aimed at women

or men. The gender-sensitive literature includes recommendations for measures that meet the needs of caregivers and care recipients and that take women's socioeconomic position into account. These recommendations would benefit more women than men because women are the majority of caregivers and care recipients. These recommendations, however, would also benefit men who take on the female gender role of caregiving or who are care recipients living in poverty.

Some of these recommendations are aimed at different levels of government, and some pose jurisdictional challenges and may even seem impossible. In times gone by, the establishment of medicare, pensions, and other programs and rights, such as women's and Aboriginal people's right to vote, seemed unlikely within the climate in which these ideas were first introduced; each garnered its share of opposition and encountered obstacles, which sometimes endured for decades before the right was obtained or the program established. Anything is possible.

5.2.1 Improving services for care recipients

Measures to improve services for care recipients would also relieve some of the burden on caregivers. Improving services involves the following:

Funding and support service issues

- adequate funding for support and institutional services (Blakley and Jaffe 1999; Lauzon et al. 1998) and federal funding to the provinces targeted specifically on ensuring access to home care and funding psychological support, pharmacare, denticare, and other currently privatized costs essential to the health and well-being of elderly, disabled, chronically ill, and recovering persons, and on restoring full funding for health care services (Morris, Robinson, and Simpson 1999)
- elder day-care services (Campbell, Bruhm, and Lilley 1998; Lauzon et al. 1998)
- convalescent homes and minor care facilities (Côté et al. 1998)
- day camps for disabled youths (Campbell, Bruhm, and Lilley 1998) and accessible day care and after-school care (Roehrer Institute 2000b)
- group homes for youth with disabilities (Campbell, Bruhm, and Lilley 1998)
- the elimination of any and all fees for service as these create barriers to obtaining services (Morris, Robinson, and Simpson 1999)
- financial assistance for home renovations (e.g., ramps, accessible washrooms) (Campbell, Bruhm, and Lilley 1998; Côté et al. 1998; Roehrer Institute 2000b)
- funding for the costs of aids and devices for people with disabilities or illness, or lending of special equipment for as long as it is required (Côté et al. 1998; Roehrer Institute 2000b)
- eligibility requirements that take into account need and not just income (e.g., need for transportation, equipment, medical supplies, special foods, medication) (Campbell, Bruhm, and Lilley 1998)

- travel allowances or transportation assistance (Campbell, Bruhm, and Lilley 1998; Côté et al. 1998)
- portable services that are attached to the individual rather than to the delivery agency (Roeher Institute 2000b)
- investment in community capacity to support children with disabilities, such as adequate funding for generic and specialized organizations and agencies (Roeher Institute 2000b)

Information and training issues

- better training for paid home care workers (Campbell, Bruhm, and Lilley 1998; Côté et al. 1998; Morris, Robinson, and Simpson 1999; Roeher Institute 2000b)
- training or information for education, child care, and leisure and recreation professionals about disability issues and inclusion (Roeher Institute 2000b)
- further training and information for health professionals and therapists about specific disability types, the social aspects of disability, the concerns of parents of children with disabilities, and community inclusion (Roeher Institute 2000b)

Continuity and coordination of care issues

- consideration of caregivers as team members and collaborators in the assessment and planning process with care recipients and community service providers (Hawranik and Strain 2000)
- better coordination of care and effective continuity of care between institutions and the home (Côté et al. 1998; Morris, Robinson, and Simpson 1999)

Human rights and quality of care issues

- the review and streamlining of the assessment process with a view to eliminating gender bias in the assessment of home care hours, and the requirement that any public or private agency receiving public funds for home care be transparent and accountable to the public in terms of gender issues in employment and the receipt of care (Morris, Robinson, and Simpson 1999)
- a transparent, confidential complaint mechanism that allows care recipients' concerns to be heard and investigated without risk of negative repercussions on their care (Aronson and Neysmith 2001)
- community services directed at the needs of care recipients (Hawranik and Strain 2000)
- the development of a national framework for access to support for children with disabilities to overcome the inconsistent levels of support, services, and inclusion across provinces (Roeher Institute 2000b)
- the development of quality standards for home care where they do not exist, and the auditing and evaluation of home care programs to ensure that those quality standards are being met and that recipients are getting the amount and type of care they need (Morris, Robinson, and Simpson 1999)
- the establishment of good-quality, accessible services in rural areas (Blakley and

- Jaffe 1999; Campbell, Bruhm, and Lilley 1998)
- the establishment of services that are culturally appropriate, which would involve working with immigrant and visible minority communities (Morris, Robinson, and Simpson 1999; Mulvihill, Mailloux, and Atkin 2000; Talbot, Soucey, and Soave 1998)
 - the establishment of good-quality, culturally sensitive, accessible home care for Aboriginal peoples in their own communities, including inner-city urban areas, designed by First Nations, Métis, and Inuit peoples (Morris, Robinson, and Simpson 1999)
 - the development of a Canada Home and Community Care Act, according to the federal government's commitment to gender-based analysis of future policies and legislation, which would be based on the principles of the Canada Health Act (accessibility, portability, universality, comprehensiveness, and public administration) and ensure access to coordinated, appropriate, publicly accountable, culturally sensitive services (Morris, Robinson, and Simpson 1999)

5.2.2 *Improving services for caregivers*

A number of studies recommended that informal caregivers (women) should not be coerced into providing care because of a lack of viable alternatives, and that any home care system should not be based on the assumption that women should provide unpaid care (Côté et al. 1998; Morris, Robinson, and Simpson 1999).

When caregivers truly do choose the caregiving role, they must be supported in this choice. Improving services for caregivers, which could lead to less stress and burden on caregivers, might also improve care for recipients. Improved services might include the following:

- information and support services that are available, accessible, flexible and responsive to caregivers' needs (Blakley and Jaffe 1999; Côté et al. 1998; Hawranik and Strain 2000)
- timely and appropriate respite care (Campbell, Bruhm, and Lilley 1998; Chappell 1993; Côté et al. 1998; Roeher Institute 2000b), which would include more hours of service; more flexibility, portability, and a wider range of respite options for children with disabilities (Roeher Institute 2000b); and ensuring that caregivers are aware of respite care and can obtain respite services at no cost (Morris, Robinson, and Simpson 1999).
- information and training for caregivers (Campbell, Bruhm, and Lilley 1998; Chapman 1995; Côté et al. 1998; Cranswick 1997; Roeher Institute 2000b). In particular, training for caregivers should include workshops on skills such as transferring a patient from a bed to a chair and lifting, bathing, and dealing with a cognitively impaired care recipient (Chapman 1995), as well as on other personal care, therapy, service coordination, advocacy, and assessment of need for technical or home accommodation (Roeher Institute 2000b). Fourteen percent of female caregivers and 12% of male caregivers interviewed in the Statistics Canada GSS wanted more information on the nature of long-term illnesses and disabilities, and 14% of female and 10% of male caregivers wanted information about how to be an

effective caregiver (Cranswick 1997).

- access to exercise and recreational facilities (Campbell, Bruhm, and Lilley 1998)
- counselling services (Campbell, Bruhm, and Lilley 1998; Chapman 1995)
- caregiver support groups (Campbell, Bruhm, and Lilley 1998) and assistance with the establishment and operation of advocacy and support organizations for caregivers (Campbell, Bruhm, and Lilley 1998; Côté et al. 1998) or some social support for caregivers (Hibbard 1996)
- networks of volunteers willing to do domestic chores (Campbell, Bruhm, and Lilley 1998)
- service club volunteer programs for caregivers and recipients (Campbell, Bruhm, and Lilley 1998)
- a toll-free telephone number at which to obtain counselling, medical, and legal assistance, as well as help in navigating through bureaucracies (Campbell, Bruhm, and Lilley 1998)
- information in public buildings about services (Campbell, Bruhm, and Lilley 1998)
- access to a directory of experts and sources of financial assistance (Campbell, Bruhm, and Lilley 1998)
- Internet access and information (Campbell, Bruhm, and Lilley 1998)
- measures to increase awareness about resources and services available to caregivers (Blakley and Jaffe 1999; Côté et al. 1998; Hawranik and Strain 2000)
- measures to meet the transportation needs for caregivers and care recipients (Campbell, Bruhm, and Lilley 1998; Chapman 1995; Côté et al. 1998)
- research on programs for caregivers in other countries that might serve as potential model programs (Lauzon 1998)

5.2.3 *Other service issues*

Other suggestions for home and community care systems included the following:

- greater collaboration across systems to enhance understanding of caregiving issues and to initiate innovative strategies to deal with these issues (Hawranik and Strain 2000)
- the establishment of a national policy council on home care to develop a vision and principles for home care, and of a task force on human resources to develop policies for improving home care delivery (Roehrer Institute 2000b)

5.2.4 *Measures to value the caregiving role*

Many of these measures would also lead to the improvement of services for caregivers and care recipients, and some might even lead to a deeper transformation, particularly if caregivers became politicized about their situation:

- specifically recognize caregivers and their needs in the development of policy (Campbell, Bruhm, and Lilley 1998; Chappell 1993; Hawranik and Strain 2000)
- engage caregivers themselves in the policy-making process (Campbell, Bruhm, and Lilley 1998; Chappell 1993) and partner with organizations representing caregivers (Tremblay et al. 1998)

- carry out research to evaluate the costs to recipients and their families of care, and compensate them for the cost (Côté et al. 1998)
- compensation for caregiving work through tax relief, pension benefits or other means (Campbell, Bruhm, and Lilley 1998), a wage (Blakley and Jaffe 1999; Masuda 1998), or some other form of financial compensation (Roehrer Institute 2000b). In particular, 15% of female and 16% of male caregivers in the Statistics Canada GSS reported that financial compensation would help them continue their caregiving work (Cranswick 1997). Morris, Robinson, and Simpson (1999) recommended a national inquiry into the wages and working conditions of paid and unpaid caregivers, which would explore remuneration for unpaid caregivers, among other issues. Côté et al. (1998) recommended a national debate on the remuneration of unpaid caregivers.

These recommendations are made in the context of a greater national and international focus on the valuation of unpaid work. Statistics Canada began collecting census data on unpaid work (including child care and housework) in 1996. The Beijing Platform for Action, to which Canada is a signatory, discusses valuing women's unpaid work. Alberta activist Beverley Smith is continuing her campaign — which includes a complaint to the United Nations — directed at the federal government to reform the pension system so that women's caregiving role does not result in poverty for women in old age. These issues are sometimes part of a larger, multifaceted debate on wages for housework, a debate in which some argue that wages for housework would entrench this role for women, others argue that it is the only solution to structural economic inequality based on women's greater caregiving responsibilities, and still others dismiss the idea for fiscal reasons. As people in the baby-boom generation reach the age in which they are becoming caregivers for adults with functional limitations, interest in recognizing the caregiving role financially may increase.

Côté et al. (1998) explored a number of reasons why the issue of remuneration is not clear-cut and why a debate is necessary. They recommended that the viability of providing remuneration be examined with the following considerations in mind:

- the difficulty of administering remuneration measures in an equitable fashion
- the risk that such measures may reduce the role of caregivers and confine them to the home
- the risk that such measures will create third-rate jobs that are poorly paid, entail no benefits, and are not subject to labour standards
- the excuse the availability of minimal pay for informal caregivers might provide to limit collective responsibility for the care of the sick and persons with functional limitations

The authors suggest guidelines to shape remuneration measures:

- Remuneration for caregiving should be universal rather than tied to the income of patients and their relatives.
- Remuneration should be based on the market value of the work.
- Participation in a program of this kind should be voluntary (allowances must not

- become an additional pressure forcing women to take responsibility for health care).
- The person receiving a salary should not be obliged to provide services and take responsibility for dependants 24 hours day, seven days a week.
- The person receiving the wage must continue to receive support, as well as public and community services.
- The dependent person must not be denied access to public services to meet needs that are unfulfilled by caregiving relatives.
- The program must ensure that patients and their caregivers are entitled to regular evaluations of their situations and to the maximum assistance needed, including psychosocial support; training; regular contact with other people in the same situation in order to talk about their experiences, reduce their isolation, and exchange services; and reentry into the work force.
- Community services and direct allowance programs that can be used independently by patients to purchase services of their choice must also be examined.

5.2.5 *Measures to value recipients of care*

Measures to value recipients of care, such as including their voices in policy-making, would also improve services and might even have a transformative impact on care recipients as individuals and as a group, empowering them, which could result in positive consequences for health and well-being. It is interesting to note how few policy recommendations fall under the category of valuing recipients of care, who are largely women seniors with functional limitations and women of all ages with disabilities. In fact, there was only one: care recipients should be consulted during the policy-making process (Aronson and Neysmith 2001).

5.2.6 *Transforming gender inequality*

Although the majority of studies focused particularly on the individual health and financial impacts of care on women caregivers and sometimes on women care recipients, a few studies made the case that receiving care and giving care are matters of citizenship and human rights, and are essential components of social and economic equality between women and men.

Among these studies are those that made the link between poverty and older women, women with disabilities, and caregivers. Not only does poverty keep women as individuals from paying for private services when public services are inadequate, poverty also prevents women's full participation as citizens in society and makes it even more difficult for women home care users, and their predominantly female caregivers, to organize for change. A number of studies recommended addressing issues of women and poverty in general as fundamental to home and community care in particular (Hooyman and Gonyea 1995; Morris, Robinson, and Simpson 1999).

A few of the broader recommendations found in the literature included the following:

- Workplace policies should take caregiving into account (Côté et al. 1998; Roehrer Institute 2000b). Almost three-quarters (70.5%) of male caregivers of seniors and almost half (46.8%) of female caregivers of seniors had full-time paid employment

(Keating et al. 1999). This finding suggests that family responsibility leave might be a beneficial way to integrate caregiving with paid work responsibilities. If caregiving is recognized and valued in the paid workplace, then more men might take on the caregiving role.

- Labour standards legislation should take into account care of relatives, providing, for example, paid family holidays (Côté et al. 1998).
- Income support and tax programs should be reviewed with a view to alleviating poverty (Morris, Robinson, and Simpson 1999).
- The recommendations of the Masuda report on women with disabilities should be implemented (Morris, Robinson, and Simpson 1999). Masuda (1998) made a number of recommendations based on cross-Canada research on women with disabilities. These recommendations involved establishing eligibility criteria for disability benefits; clarifying entitlements to services, rights, and help with appealing assessments; covering disability-related costs; and other points relating primarily to financial security for women with disabilities.
- A gender analysis of all health reforms should be conducted and necessary action taken to ensure fairness (Côté et al. 1998).
- Armstrong and Kits (2001) developed a series of questions that can and should be applied to all policy, legislation, and regulations: Are caregiving and care receiving voluntary? Can caregiving be equally shared among women and men? Can caregiving be culturally sensitive without it being based on inappropriate assumptions about cultural groups and without contravening other equity principles? Can the assumptions made about personal relationships related to caregiving be justified? Is there recognition of the different interests that need to be balanced in caregiving? Is need defined in ways that exclude some groups while privileging or stigmatizing others? What are the long-term consequences? Are the objectives reinforced or undermined by other legislation, regulations, or policy? Are the contributions of care recipients recognized and the skills required for giving care acknowledged? Are current patterns themselves constructs of policy or does policy reflect actual preferences and practices?

Because frail older women, women with disabilities, and caregivers tend to be isolated, exhausted, of low income, and inactive in democratic structures, they are not in a position to draw much public awareness to their situation, nor to elicit much political commitment to action that will lead to change.

The other issue of concern is how caregiving is compartmentalized, which serves to disguise the widespread nature of gender inequality in caregiving. For example, paid caregiving is treated as a separate issue from unpaid caregiving and care receiving, even though an even greater majority of paid than unpaid caregivers are women and they face many of the same issues of isolation, low income, poor working conditions, and gendered expectations — expectations that then have a direct impact on the quality of care experienced by recipients. Another example is how caregiving of people with disabilities, seniors, and people with acute conditions and illnesses is treated as a separate issue from caregiving of children and unpaid domestic work in support of an able spouse, which is also the same gendered caregiving role and has an impact on women's financial security, and to which some of the same broader solutions might apply.

Many other strategies for gender equality, those that are more far-reaching and transformative in nature, can be found in other types of literature. This paper, however, only discusses strategies found in the home care literature.

Some people may question why social transformation toward repeated federal and provincial government commitments to gender equality should be part of policy-making on home and community care. The answer is that, as currently structured, home and community care policies and practices are not only operating in a context of gender inequality, but also are helping to create it.

5.3 CONCLUSION

The majority of studies on home and community care does not take gender into account, apart from occasionally pointing out that most family caregivers are women. Of the studies that do take gender into account, some point to the broader context of women's socioeconomic inequality, but most focus on responses and policy recommendations that would enable women caregivers to better cope with the role that has been thrust on them. These recommendations certainly are of value for providing some needed relief to caregivers on a day-to-day basis, but they cannot be viewed as the end of the story.

Fewer studies look at the gendered nature of receiving care, particularly in the context of socioeconomic gender inequality that leaves many older women poor and alone. A few studies also link the gendered nature of paid home care work with unpaid work and the receipt of care, but few of these make recommendations about measures to deal with the root of the socioeconomic inequality and the cultural expectations that women will do caregiving work for little or no pay. Nevertheless, these studies have provided a wealth of practical recommendations that could be applied immediately and, if implemented, would greatly ease and improve the lives of care recipients.

The studies that deal with the impact of health care restructuring on women portray the state as one that places short-term economic considerations above concerns for the marginalization of its citizens, particularly older women and women with disabilities. In fact, the studies claim that the state uses structural gender inequality to limit current expenditures at the expense of the future financial security, health, and lives of women. Governments face an uphill battle to counteract this prevailing notion, and must do so by

placing equality and citizenship goals front and centre in the development of home and community care policy.

The need for care is simply taken for granted, and certainly there will always be a need to care for some individuals. However, another approach to this issue was outlined in one study. The most significant predictor of the need for care was health status, not age. The authors suggested that the assumption should not be made that an aging population will necessarily require more care, as long as the next cohort of seniors is in better health (Keating et al. 1999). One way to reduce the need for care is to invest in preventative health measures and adequate incomes for Canadians, so that eventually seniors will be leading longer, active, disability-free lives.

Gender-sensitive studies may lead us to valuable conclusions that are different from those that emerge from research that is not gender sensitive. For example, because a study does not differentiate between women and men caregivers, the reader may conclude that the burden of caregiving is not that great. The reader may find that caregivers' health is adequate and that caregivers do not suffer severe financial or personal consequences due to their caregiving. When a study differentiates between men and women caregivers, a different picture emerges: one group of caregivers does much less, and their caregiving has less impact on them than is the case in the other group, which does much more and for which the health and long-term financial effects are severe. Thus, research that is not gender sensitive can underestimate caregiver burden and health, personal, and financial effects because the one-third of caregivers who are men tend not to give as many hours of care as women and give up less in terms of their career and personal life.

Since gender-sensitive research tends to be performed by researchers with a grasp of socioeconomic gender differences, such research may pay more attention to issues of income and poverty. These studies ask the questions about financial implications, which are reflected in recommendations such as providing a travel allowance or transportation assistance; reviewing income support, disability-related programs, and tax programs to alleviate poverty; establishing workplace policies that take caregiving into account; compensating caregiving work through tax relief, pension benefits, a wage, or some other form of financial compensation; providing timely, appropriate, low-cost respite care; and including counselling services for caregivers and recipients as part of free and available services. This perspective is missing in the mainstream health care debate about user fees, for example. That debate centres on how the government can afford care. What is missing is the gendered perspective of how women can afford to continue giving more and more unpaid care and how they can access a health system when their wages are low or nonexistent.

Gender-sensitive research reveals that men and women are treated differently as care recipients, a point — completely missed in research that ignores gender — that has policy implications for the home care assessment process.

Sometimes, what is valuable about gender-sensitive research is the perspective of the researchers, which tends to be oriented toward social justice. These researchers raise issues such as the citizenship rights of caregivers and care recipients. In most of the literature, care recipients in particular tend to be viewed as objects of care rather than as

human beings with social and political rights. The majority of care recipients are women seniors and women with disabilities. They are often not viewed as women and therefore researchers and others underestimate their vulnerability to violence experienced by women, such as sexual assault and spousal abuse. Gender-sensitive studies stress the importance of involving caregivers and care recipients in decision-making at local, provincial, and federal levels, inclusion that can only lead to more responsive, reality-based policy.

Gender-sensitive research does not just provide answers, it also asks important questions, such as a series of questions developed by Armstrong and Kitts (2001) for application to all policy, legislation, and regulations.

Not all of the recommendations of gender-sensitive research are gender specific, but they are developed using research that was gender sensitive and consultative of the needs of women and men. As most of these recommendations are geared to building a better home and community care system and alleviating the burden on caregivers, they will naturally have a greater impact on women, as the majority of caregivers and recipients, than men. These recommendations, however, will also benefit men who have taken on the traditionally female gender role of caregiving, and men who find themselves in similar economic situations to the majority of women with functional limitations. Even though statistically not as many men as women perform the caregiving role, and statistically fewer men give a lot of their time to caregiving, some men are deeply involved in unpaid caregiving, and they, as well as women, will benefit from the recommendations of gender-sensitive research.

As discussed, many of the recommendations made in these studies apply equally to women and men. Some, such as a number of the caregiver recommendations that are designed particularly with women's needs in mind, would also benefit men in those roles. That being said, women and men differ on average in terms of socioeconomic status, life experience, and the cultural expectations made of them. Policy decisions about the following issues have a different impact on women who are care recipients or caregivers than on men:

- which services are publicly funded
- assumptions about the type and level of care to be provided by family members or other unpaid caregivers
- coverage for out-of-pocket expenses, including drugs, medical supplies, assistive devices, and therapies
- the degree of attention to the needs of caregivers, as well as care recipients, including physical and mental health and opportunity costs such as loss of employment

The purpose of gender-based analysis is to develop good, evidence-based policy founded on a complete picture of how women and men are affected.

If home and community care policies are not to entrench and exacerbate gender inequality, they must take gender differences into account.

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Due to limitations of time and space, not all of the sources identified below were reviewed. They have been coded in terms of whether they were gender specific, recent, Canadian, specifically about home and community care, and took the diversity of the population into account. Those sources that were reviewed for this synthesis paper are marked with the symbol U .

PRIORITIES

- & Gender-specific: The document is specifically a gender analysis or about gender impacts, rather than home care research that mentions women but does not focus on women or gender.
- Home care-specific: The document is specifically about home care or caregiving of people with functional limitations rather than being one about the health care or social support system in general with references to home care.
- È Canadian: The document is about the Canadian situation.
- ± Recent: The document was published between 1998 and 2001.
- { Diversity-specific: The document focuses on a target population: Aboriginal peoples; immigrant, refugee, or visible minority communities; people with disabilities; lesbians and gay men; people living in remote or rural settings; and other specific populations.

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