

Development of screening and assessment tools for family caregivers

NA 145

Nancy Guberman*, Janice Keefe**, Pamela Fancey**,
Daphne Nahmiash***, Lucy Barylak****

Final report submitted February 15, 2001.

With the participation of
Jennifer Beeman*, Amanda Grenier*, Mary Lou Robertson** and Lucie Vezina***

This project was supported by a financial contribution from the Health Transition Fund, Health Canada. The views expressed within do not necessarily represent the official policy of federal, provincial or territorial governments.

- * School of Social Work, Université du Québec à Montréal, C.P. 8888, Succ. Centreville, Montréal, H3C 3P8
- ** Family Studies and Gerontology, Mount St. Vincent University, Halifax, Nova Scotia
- *** École de service social , Université Laval
- **** Caregiver Support Centre, CLSC René-Cassin/Institute of Social Gerontology

Development of screening and assessment tools for family caregivers

TABLE OF CONTENTS

- 1.Executive summary**Error! Bookmark not defined.
- 2.Acknowledgements**..... 7
- 3. Objectives/goals/relevance of project** 9
- 4. Project Activities/Methodology**..... 10
 - 4.1. PHASE I - DEVELOPMENT OF THE SCREENING AND ASSESSMENT TOOLS 10
 - 4.1.1. *Informing the content of the tools*..... 10
 - 4.1.1.1. Literature search of validated tools 10
 - 4.1.1.2. Collection of non-validated tools 10
 - 4.1.1.3. Focus Groups 11
 - 4.1.2. *Creating the tools* 11
 - 4.1.2.1. Team Meetings 11
 - 4.1.2.2. Pretesting – Informal and Formal 11
 - 4.1.2.3. Advisory Committee and Statistical Consultant..... 12
 - 4.1.3. *Finding sites for testing the tools* 12
 - 4.2. PHASE II -TESTING THE TOOLS 12
 - 4.2.1. *Recruitment of the Sample and Administration of the Tools* 12
 - 4.2.2. *Development of the Training Sessions*..... 13
 - 4.3. PHASE III – VALIDATING THE TOOLS..... 13
 - 4.3.1. *Screening tool – statistical validation* 13
 - 4.3.2. *Assessment tool – statistical validation* 13
 - Internal Consistency..... 14
 - Limitations of Kappa 14
 - 4.3.3. *Qualitative validation of the tools* 14
- 5. Description of project results** 15
 - 5.1. DEVELOPMENT AND VALIDATION OF THE SCREENING TOOL..... 15
 - 5.1.1. *Design of the screening tool*..... 15
 - 5.1.2. *Description of the sample* 15
 - 5.1.3. *Internal consistency*..... 15
 - 5.1.4. *External consistency*..... 16
 - 5.1.5. *Other variables*..... 17
 - 5.1.6. *Discussion of results*..... 18
 - 5.1.7. *How the tool affected the elements of the HTF Evaluation* 18
 - 5.2. DEVELOPMENT AND VALIDATION OF THE ASSESSMENT TOOL 19
 - 5.2.1. *Introduction* 19
 - 5.2.2. *Design of the assessment tool*..... 19
 - 5.2.3. *Description of the sample* 20
 - Caregiving Situation 20
 - 5.2.4. *Inter-rater reliability* 20
 - 5.2.4.1. Assessment Areas..... 20
 - 5.2.4.2. Key Areas of Concern..... 23
 - 5.2.5. *Internal consistency*..... 26
 - 5.2.6. *Discussion* 26
 - 5.3. HOW THE ASSESSMENT TOOL AFFECTED ELEMENTS OF THE HTF EVALUATION FRAMEWORK..... 27
 - 5.3.1. *The quality of care*..... 27

5.3.1.1. Objective 1: Increases understanding/awareness of what it means to be a caregiver.....	28
5.3.1.2. Objectives 2 & 4: Identifies caregiver issues and key concerns.....	29
5.3.1.3. Objective 3: Quickly identified needs.....	29
5.3.1.4. Objective 4: Allows for the development of an efficient service plan	30
5.3.1.5. Beyond our objectives: Long-lasting impacts of the tool.....	30
5.3.2. <i>How does the tool affect access to health services?</i>	31
5.3.2.1. Changes in the way services are delivered which took place during the study and led to increased access to services	31
5.3.2.2. Changing the notion of client & health to assure that caregivers have access to services.....	32
5.3.2.3. Increased awareness of the lack of resources to meet caregiver needs	32
5.3.2.4. Given the diversity of caregivers and caregiver situations, are the tools appropriate for ensuring access for all?.....	32
5.3.3. <i>Integration of a new group of stakeholders into the health system</i>	33
5.3.3.1. Legitimises caregivers' right to be heard	33
5.3.3.2. Systematic & innovative: raises questions about the place of caregivers in home care programs ..	34
5.3.3.3. Reinforces agencies' caregiver orientation	34
5.3.3.4. Provides a rationale for directing services to caregivers & justifies intervention strategies	34
5.3.4. <i>Were there any health impacts or caregiver well-being issues which emerged?</i>	35
5.3.5. <i>Cost-effectiveness</i>	35
5.3.6. <i>What lessons were learned about implementing and testing the tools which might be useful to other regions/programs/settings? - Transferability</i>	35
5.3.6.1. Actively including stakeholders from conception to evaluation	36
5.3.6.2. Assuring standardisation	36
5.3.6.3. Integrating research with the everyday demands of practice.....	37
5.3.6.4. Ethical questions	38
5.3.7. <i>In summary: Lessons for Successful Implementation</i>	39
5.3.8. <i>Challenges for the transferability and future implementation of the tools</i>	39
Pre-requisites to implementation.....	39
5.3.9. <i>Unanticipated outcomes</i>	41
5.3.10. <i>Implications for program/service development</i>	41
5.3.11. <i>Potential policy implications</i>	41
6. Dissemination Plan	41

Executive summary

The goal of this project was to develop appropriate instruments for assessing and evaluating the specific needs of family caregivers which take into account their reality and conditions and which situate them as essential partners with the formal system in the care of dependent adults.

This project's specific objectives were:

- 1) to develop a screening and an assessment tool for assessing the context, the conditions and the needs of family caregivers;
- 2) to test and evaluate these tools in CLSCs in Quebec and in home care agencies in Nova Scotia.

The primary audience for this project is composed of policy-makers, administrators and practitioners in home care and more widely in front-line care. Our secondary audience includes caregivers, academics, training institutions and the general public.

Methodology

The screening and assessment tools were developed between April 1999 and February 2000. To ensure that the tools were sufficiently comprehensive to be applied to the array of home care services in Canada and a wide variety of caregiving situations and to ensure that we were aware of any existing tools, this initial phase was designed to incorporate a number of approaches to inform the development of the tool. These three approaches or methods included: a literature search of validated tools which found 82 useful instruments, but none that addressed a range of caregiver issues or that isolated caregivers' service needs; the collection of non-validated tools found through a literature search, contact with key informers from around the world and contact with public, private and non-profit agencies throughout North America; and nine focus groups with family caregivers and community care practitioners to help identify the key elements required for a caregiver assessment tool.

Based on results from these three methods, the team developed various drafts of the tools which underwent informal pre-testing during this period. A final draft of each tool was formally pretested in December-January 1999-2000 and the final test versions were printed in February. During this same period, the team selected specific agency sites from the provincial home care programs in each province (three regions of Home Care Nova Scotia and five CLSCs), to ensure a diversity of representation from urban and rural areas. Home care programs were selected because the assessment was intended for implementation at the community level, and because it was felt that assessors in home care had the experience and training to conduct the assessment appropriately during the testing period.

A purposive convenience sample from the 7 research sites was used to test the assessment tool. Assessors within these programs were asked to select cases known to have a family member involved and invite them to participate. In total, 168 family caregivers were interviewed twice; first by one assessor and within 7 working days, by a second assessor. Data collected on the summary page of the assessment tool were analyzed to determine inter-rater reliability amongst 15 assessment areas and 18 key areas of concern and the internal consistency between the assessment areas and key areas of concern.

The screening tool was administered by intake workers with consenting caregivers requesting services for the first time, immediately after completion of the intake interview and having obtained consent. The screening tool and follow-up interview with the Caregiver Burden Screen (Rankin et al., 1994) were administered to 87 caregivers, but 11 of the completed tools could not be used in the validation study for a variety of reasons. Results are thus based on a sample of 76 caregivers. The screening tool was validated for its internal and external consistency using Cronbach's Alpha reliability and Pearson's correlation coefficients.

Results

The screening tool

Two validated tools for assessing caregivers, one to be used at intake and one, as a comprehensive assessment, were the main outcomes of this project. The Caregiver Risk Screen has been developed which proposes a more systematic method of determining the situation of family caregivers. The purpose of the screening tool is to assess the level at which a caregiver's physical and/or mental well-being is at risk and whether the care being provided is adequate. A level of risk is determined to establish the urgency of intervention.

In the external consistency measures all of the correlations are high and significant showing a good match between the validation instrument and the screening tool. Regarding the internal consistency of the screening tool, all the items are significant (Alpha = 0.88).

This is the only screening tool which has such a variety of diverse elements which contribute to a portrait of risk to the caregivers physical and mental health. It therefore seems pertinent to recommend it to other agencies and provinces to use and test further.

The assessment tool

The Caregiver Assessment Tool is designed to collect information on many different areas of a caregiver's situation, and to pinpoint from this information the key areas of difficulty being experienced and the types of services or support that would best assist the caregiver. It is intended to collect information from the caregiver's perspective and enable the assessor to contribute her/his perspective when summarizing the key concerns for the situation.

The results of the inter-rater reliability and internal consistency tests suggest that, for the most part, this comprehensive tool is a valid and reliable instrument to understand caregivers' needs and situations. A reasonable level of agreement between assessment A and B exists between the 15 assessment areas and the 18 key areas of concern. The test for internal consistency indicates that the scoring of assessment areas informs related key areas of concern.

Based on analyses of focus groups and interviews, we can advance that the tool increases worker understanding and awareness of what it means to be a caregiver, enables assessors to identify key caregiver concerns, and to do so within one or two evaluative visits. The tool changed assessors' attitudes, and occasionally their practice with caregivers, while for caregivers, as noted by both assessors and administrators; the tool gave them recognition and validated their concerns and everyday efforts. The authors conclude that the assessment tool has the potential to change levels of satisfaction with the quality of caregiver/provider relationship from both the provider's and the caregiver's point of view (which it did even within the framework of a simulated exercise), and that it will lead to changes in the technical appropriateness of intervention by informing practitioners of elements in the context of home care recipients which have been given little attention until now but which impact on the adequacy of interventions. The tool also led to changes in assessors' understanding of the service and resource needs of caregivers and when these services and resources are available will lead (and did lead in some cases) to a better access to services for caregivers. The majority of workers and administrators believe that the assessment tool is appropriate for use in diverse settings and situations, and that it is adapted to various ethno-racial and cultural groups, as well as urban and rural populations.

Some of the implementation strategies which contributed to these successful outcomes include bringing all the stakeholders on board in an active way; standardization of procedures across the sites; attempting to take into

consideration the difficulties of agency-based research; and providing on-going consultation and support to practitioner-researchers and administrators.

Recommendations and policy implications

To facilitate future implementation of the tools it is felt that caregivers must become an agency priority; that the purpose, and use of the tools be clearly defined; that the tools be integrated with existing tools; that staff be brought on-board from the outset; and that training be assured.

However, a major challenge stands in the way of future implementation: presently caregivers neither have status within home care policy nor within the home care service package. Based on our findings, we would question the idea that we can continue to automatically assume caregiver involvement at the level that policy implicitly does today without seriously compromising their well-being. Caregivers must be specifically named in health-care and home care policies and they must be targeted as having specific needs for ensuring their well-being. Their well-being must be of equal priority in the health-care system as the well-being of the disabled persons they care for. Within agencies, because of insufficient resources, lack of time and inappropriate tools, there is a culture of normalcy regarding the situation of caregivers. To that extent, it is crucial that government allocate financial resources to support this new group of potential clients and to develop the services and resources which caregivers need in order to maintain their responsibilities without undue negative effects to themselves.

The contribution of the screening and assessment tools is that they enable practitioners and program developers to have a comprehensive understanding of caregivers' situations and identify the services and resources needed to support them. We recommend their adoption by provincial home care programs.

Acknowledgements

This report and the study which it describes are the result of a collaborative effort involving many people at different levels. We are deeply indebted to every one of them.

First, the principal researchers were supported every step of the way by our research coordinators: Jennifer Beeman, Amanda Grenier, Mary Lou Robertson and Lucie Vézina, even when it took a certain leap of faith to believe we could achieve what we had set out to do. Without their talent, organizational skills, good humour and determination in the face of adversity, we would never have made it to this stage. We do not have the words to express our heartfelt appreciation of their contributions to the project.

The research was also the work of our devoted research assistants: Marie-France Cimon, Claire Chaume, Hélène Dagenais, Judy Dickinson, Shawna Elliott, Donna Kozziel, Noreen Millar, Trish Plamondon, and Anne-Marie Royer. We also acknowledge the indispensable contribution of Pierre Maheu, which was only cut short by his untimely decision to take early retirement. Margot Knox offered invaluable advice as our statistical consultant, as well as doing much of the statistical analysis for the screening tool.

We gratefully acknowledge the work of Martine Jutras-Legault who did the layout and design of the test version of the assessment tool, Joseph Caron who did the layout of this report, Marie-Luce Giroud and Yvon Simard who translated various documents throughout the course of the project, and practitioners at COMSEP, a literacy group in Trois-Rivières, who offered astute recommendations for rewording the questions of the assessment tool to make them more user-friendly.

Our sincere recognition to the following administrators and agencies who so generously and enthusiastically agreed to participate in this adventure: Sandra Cook, Home care Nova Scotia – Eastern, Western and Central Regions; André Giguère, CLSC Lévis-Desjardins; Guy Poulin, CLSC Bellechasse; Joëlle Khalfa, CLSC René-Cassin/Institute of Social Gerontology; Piere Jolin, CLSC Rivière-de-Prairies; Louise Favreau, CLSC la Pommeraie. We thank, in particular the administrators and supervisors who accepted to be interviewed or who assisted in the implementation of the project.

Many people gave freely of their time to participate in consultations in the elaboration stage of the project. Forty-one caregivers, 37 practitioners, and 4 administrators participated in focus groups, and many other people made themselves available for informal consultations. Their judicious comments were extremely valuable for helping us develop our conception of the tools and we are appreciative of their contribution. As well, we extend our gratitude to thirteen students in a class at Mount Saint Vincent University who conducted informal pre-tests of the assessment tool. Special recognition goes to members of the Caregiver Advisory Committee of the Caregiver Support Centre, CLSC René-Cassin/Institute of Social Gerontology who played an active part in commenting various drafts of the assessment tool.

Six people agreed to sit on our advisory committee which was particularly active in the period preceeding the testing of the tools. For their support and advice we thank Ilona Horgen, Alzheimer Society of Canada, Pierre Jolin, Association. des CLSC-CHSLD, Pam Martin, CHCA, Dr. Murray Nixon, Provincial Medical Advisory for Home Care Nova Scotia, Fay Porter, VON Canada, and Dr. David Pedlar, Veteran's Affairs Canada.

Words can not express our recognition of the contribution of caregivers to this project. Besides those mentioned above, ten caregivers accepted to pre-test the assessment tool and more than generously met with researchers for two interviews in the weeks before Christmas, 1999. Over two hundred and sixty other caregivers also agreed to donate hours of their time to test our tools. We are deeply grateful for their selfless participation and can only hope that this project in some way contributes to the recognition of caregivers' right to be served by the health-care system.

Our profound recognition goes to the front-line workers who accepted to put on a researcher's hat and test our tools. We can not sufficiently express the importance of their participation. Their role was not only pivotal to the

completion of the study, but their involvement ensured that the tools would be tested in the most natural environment possible and thus adapted to real life practice.

Finally, this project might have remained just a good idea were it not for funding from the Health Transition Fund of Health Canada which allowed us to realize it.

To all of you, thank you.

Nancy Guberman

Janice Keefe

Pamela Fancey

Daphne Nahmiash

Lucy Barylak

3. Objectives/goals/relevance of project¹

The goal of the present project was to develop appropriate instruments for assessing and evaluating the specific needs of family caregivers which take into account their reality and conditions and which situate them as essential partners with the formal system in the care of dependent adults

The need to develop such tools was identified by both the researcher and practice partners of the research team as a result of their analysis of caregivers' lack of formal status within the health care system and how this translated into the difficulty, and even the impossibility, for the formal system to respond to their well-documented needs. This reality exists despite the fact that all North-American studies on who is offering support and services to dependent persons in the community have amply demonstrated that community care is mainly family care and that family care can too often be summed up as care by women in the family. Indeed, data from the 1996 General Social Survey (Cranswick, 1997) examining social and community support by Canadians suggests that 2.8 million individuals provided help to someone with a long term physical or health limitation. And yet, research has also shown that no real comprehensive policy or plan of service allocation exist to support family caregivers.

The negative impact of this situation on family caregivers in terms of their physical and mental health, their finances, their workplace participation and their family and social responsibilities has also been amply documented (Brody, 1990; Cantor, 1983; Guberman et al, 1993; Hooyman, 1990; Keefe & Fancey, 1997, 1998; Keefe & Medjuck, 1997). Almost half of all caregivers adjust their social activities because of caregiving. Though emotional strains are the most frequent and severe consequences for caregivers, significant numbers experience physical and financial strains as well. Cited impacts of caring on work place participation include absenteeism, modifying work schedules, refusing promotions, reduced productivity, and partial or total withdrawal from the labor market (Guberman et al., 1993; Keefe & Medjuck, 1997; McKinnon & Odynak, 1991; Neal et al, 1993; Scharlach, Lowe & Schneider, 1991). The 1996 General Social Survey (Cranswick, 1997) reveals that half of the caregivers employed outside the home turn to these arrangements. However, all of these arrangements have significant impacts on caregivers' financial situation both in the short term because of immediate loss of income and in the long term because of the consequences on pension levels. Despite this, in the past few years, pressures on family members to become caregivers have only increased as health systems move away from hospitalisation to day surgery and home convalescence.

It is within this context, that caregivers are increasingly being identified by health and social service practitioners as having specific, often unmet, needs for support, respite, information and advocacy, which should translate into interventions aimed specifically at them. However, caregivers are not officially clients of the health and social service system; the files are opened in the name of the care recipient. Recent research (Lavoie et al, 1998, Maheu & Guberman, 2002, Ward-Griffin & McKeever, 2000) reveals that caregivers are seen by policy makers and practitioners in different lights, sometimes as co-clients with the care recipient, sometimes as resources which must be mobilised and educated to meet the needs of the care recipient, and occasionally as co-workers or partners. This confusion and ambiguity has led to a situation where, in fact, caregivers' needs are rarely considered in practitioners' evaluations and interventions (Guberman & Maheu, 2000).

At the present time, no known model of intervention and appropriate tools for assessing caregivers' situations and needs exist in Canada (VON, 1998). It is thus imperative to develop and validate such tools so as to assure the well-being of caregivers and ultimately, the people they care for.

This project's specific objectives were thus:

- 1) to develop a screening and an assessment tool for assessing the context, the conditions and the needs of family caregivers;
- 2) to test and evaluate these tools in CLSCs in Quebec and in home care agencies in Nova Scotia.

¹ Numbering of sections follows that proposed in "Guidelines for Final Administrative Report".

4. Project Activities/Methodology

4.1. Phase I - Development of the Screening and Assessment Tools

At the outset it is important to indicate that this project is the result of a research-practice partnership between university researchers and a front-line agency, the CLSC René-Cassin/Institute of Social Gerontology, represented by the Caregiver Support Centre Coordinator, as a full team member throughout the life of the project. The importance of the interaction between these two partners in conceiving and testing the tools can not be overstated.

4.1.1. Informing the content of the tools

The screening and assessment tools were developed between April 1999 and February 2000. To ensure that the tools were sufficiently comprehensive to be applied to the array of home care services in Canada and a wide variety of caregiving situations and to ensure that we were aware of any existing tools, this initial phase was designed to incorporate a number of approaches to the tools' development.

The initial development of the tools was informed by three methods:

4.1.1.1. Literature search of validated tools²

First, we conducted an extensive review of validated screening instruments in the scientific literature and established a directory of published, validated caregiver assessment tools. We found over 1000 abstracts. This initial selection was narrowed down to scientific articles that contained measurement instruments used for caregivers of the ill or disabled who provided care at home with good psychometric properties. Following this process, 119 instruments were kept, and further review narrowed these selections down to 82 useful instruments. In spite of the many tools developed for use with caregivers, the team did not locate any validated tools that addressed a range of caregiver issues, or that isolated caregivers' service needs. Those that did exist were generally psycho-social scales which measured isolated variables such as burden, depression, social support, etc. Most were designed for a specific population (e.g. caregivers of persons with dementia).

The literature search also helped us choose an existing validated instrument for validation of our screening tool. We sought an instrument that was short, validated in English and in French and containing multidimensional variables. We finally selected the Caregiver Burden Screen developed by Rankin et al. (see Appendix H).

4.1.1.2. Collection of non-validated tools³

Second, we collected non-validated caregiver assessments developed by community-based agencies around the world, as well as research on non-validated tools which described what they should contain. We turned to three main sources to obtain these documents:

a) a literature search of nine major databases in the health and social science fields was conducted to identify articles that discussed or presented a non-validated tool, or that contained resource information for the project. In addition to the database search, manual searches of significant journals in the fields of gerontology, social work, and nursing were completed. Review of the 1060 potential articles found only 32 useful for the data collection. Only 4 articles produced specific non-validated caregiver assessment tools.

b) contact with front-line agencies through communication with key informants who could provide information on the existence of caregiver assessments in Canada and other countries. Contact was initially made via fax or email with 61

² See Appendix C for the full literature review (French version).

³ See Appendix C for the report on the review of the non-validated tools.

sources in 15 countries, including Canada. In total 32 (52%) responses were received. Communication was established with two other caregiver assessment projects underway in the Netherlands and Australia, as well as *The Carers Impact Project* and subsidiary projects in the UK that are examining the impact of carers' assessment legislation in that country. A total of thirteen (13) caregiver assessments and twenty (20) informative articles/reports were collected through this process.

c) contact with agencies to comprehensively identify non-validated caregiver assessment tools in existence at the community level in North America. Contact was initiated with 245 public, private, and non-profit agencies throughout the United States and Canada that provided home care or support services to family caregivers. In total, 12 caregiver assessments and 34 general assessments containing a section on caregivers were collected from within North America, as well as 5 resources useful for informing the methodology of various elements. An extensive database was developed to summarise and analyze the correspondence data and the elements identified within the tools collected.

4.1.1.3. Focus Groups

Third, nine focus groups were held with family caregivers and community care practitioners in Quebec City, Halifax, and Montreal to help identify the key elements required for a caregiver assessment tool, and one with home care administrators in Montreal.

Participants in the caregiver focus groups were recruited through a variety of methods with the goal to assure a heterogeneity of participant characteristics (nature of the caregiving relationship, health problem of the care recipient, community location, discipline of practitioners, etc.). The caregivers who attended cared for elderly relatives as well as spouses and adult children with disabilities or mental health problems. In all, 41 caregivers, 37 practitioners, and 4 administrators participated.

Besides questioning participants on the content of the tools, the researchers also raised questions concerning the preferred format for the tool and other comments as to its implementation. The data gathered through the focus groups was instrumental in determining the choice and wording of many of the questions in the assessment tool (see Appendix C which presents the analysis of the focus groups).

4.1.2. Creating the tools

Data collected was analyzed in team meetings and several drafts of the tools were produced and submitted to various forms of consultation.

4.1.2.1. Team Meetings

The researchers met over a number of in-person meetings and teleconferences between August of 1999 and February of 2000 to review the results of the previous three search methods and to develop various drafts of the tools. In all, four key drafts of the assessment tool and two of the screening tool were developed over this time period.

4.1.2.2. Pretesting – Informal and Formal

Preliminary, informal pretests were conducted to gather input on an early draft of the assessment tool. A number of persons, including students in a case management class and collaborators of the researchers, participated in this process to provide some input on the content and implementation of this draft of the tool. A group of caregivers also reviewed the tool and met with the researchers to provide feedback on the design and content of the tool. The researchers focused on a number of issues during these initial pretests including degree of comfort of caregivers with the tool, its wording and its organisation, the relevance of each question and the ability of the tool to help assessors identify key areas of concern.

Once we had arrived at a final draft of the tools, we conducted formal pretests. For the assessment tool, this process was completed by members of the research team, using the same methods that would be used during testing for inter-judge reliability. Thus two different researchers assessed, separately, each caregiver who participated in the pretests.

The screening tool was tested by in-take workers in two of the participating CLSCs. Both tools were pretested in English and in French. Following the pre-tests, final modifications were made to both tools.

4.1.2.3. Advisory Committee and Statistical Consultant

The researchers were supported during the development phase by an advisory committee comprised of administrators and government officials from the sectors of home care and gerontology⁴. This committee reviewed the early drafts of the assessment tool and provided feedback on its content, design, and implementation. As well, the researchers consulted a statistician during the development of the various drafts to ensure the questions and summary section were being designed in a way that would enable the researchers to test the tool's inter-rater reliability.

4.1.3. Finding sites for testing the tools

The research team had designed the testing phase to include the participation of seven (7) home care agency sites – four (4) in Quebec and three (3) in Nova Scotia. They selected specific agency sites from the provincial home care programs in each province to ensure a diversity of representation from urban and rural areas. Home care programs were selected because the assessment was intended for implementation at the community level, and because it was felt that assessors in home care had the experience and training to conduct the assessment appropriately during the testing period. The team also wanted to collect feedback from assessors on the suitability of the assessment for a home care setting.

While a similar collaboration agreement was used for all agencies, the process of negotiating these arrangements was approached differently in Quebec and in Nova Scotia due to varying infrastructures in the provincial home care programs. A copy of the collaboration agreement is provided in Appendix E. It outlines the specific commitments of the agency and the research team.

4.2. Phase II -Testing The Tools

4.2.1. Recruitment of the Sample and Administration of the Tools

A purposive convenience sample from the 7 research sites was used to test the assessment tool. The project specifically targeted caregivers of clients of provincial home care programs. Assessors within these programs were asked to select cases known to have a family member involved and invite them to participate. The quota per agency was set at 25. The project aimed to include caregivers in rural and urban settings, caregivers whose primary language was French and English, caregivers to older adults (approximately 70%), and a mix of relationships (e.g. spouse, child, sibling, parent). In total, 168 family caregivers were interviewed twice. First by one assessor and within 7 working days a second assessor. Assessments averaged 90 minutes to administer and were conducted at a place of convenience for the caregiver.

The screening tool was administered over the telephone by intake workers of the agency sites to family members requesting services from the agency for the first time. This exercise was done immediately after completion of the agency intake interview and having obtained consent. Within four days, a researcher telephoned the caregiver to administer the Caregiver Burden Screen (Rankin et al., 1994) as the validation measure for our tool (see Appendix H). We had hoped to recruit 25 participants per site for a total of 175. The screening tools and follow-up interview were in fact administered to 87 caregivers and 11 of those completed were not able to be used in the validation study for a variety of reasons. Results are thus based on a sample of 76 caregivers, which was sufficient for validation.

Recruitment of participants proved to be more difficult than was expected due to several reasons: professionals' lack of time, situations which were not eligible, for example, caregivers in crisis; the manner in which intake is organised in some agencies; and notably the fact that many agencies receive few requests for services from caregivers. Administration took between 5 and 45 minutes, however the majority only took between 10 to 15 minutes (the average time was 14 minutes).

⁴ See Appendix M for list of Advisory Committee members.

The testing phase included two important activities prior to actual testing: development of the training sessions and assessment tool user guide, and training the home care assessors and screeners to administer the tools.

4.2.2. Development of the Training Sessions

Training sessions were developed to orient practitioners on their role in the testing phase, the content of the tool, the potential ethical implications, and the procedures of the testing phase in order to implement the tools effectively. The sessions also served as a method for getting to know the assessors, for learning of any challenges with their current role that might impact on the testing phase (e.g. time constraints, high workloads), and for ensuring that they were properly instructed on the tool.

To ensure standardisation of the administration of the tools across the sites, the team created both a user guide to accompany the tool, and a training guide (see Appendix D) for use by the various members of the research team when conducting the training sessions, as well as writing several handouts on specific issues for assessors (e.g. background information on the project, inclusion and exclusion criteria for choosing caregivers, a check list of subjects to be covered when recruiting caregivers especially with regard to ethical considerations, etc.). The user guide was eventually integrated into the final tool and consists of instructions placed on each left-hand page of the assessment, to correspond to the questions on the right-hand page (see Appendix B). Instructions include the purpose of the question, indications on how to fill out the question and definitions and/or examples for specific terms. Detailed information on the training manual, the user guide and the training sessions is available from the team members.

4.3. Phase III – Validating The Tools

4.3.1. Screening tool – statistical validation

The screening tool was validated for its internal and external consistency using Alpha Cronbach measures.

4.3.2. Assessment tool – statistical validation

Data collected on the summary page of the assessment tool were analyzed to determine inter-rater reliability amongst 15 assessment areas and 18 key areas of concern and the internal consistency between the assessment areas and key areas of concern.

FIGURE 1. VALIDATION OF THE ASSESSMENT TOOL: INTER-RATER RELIABILITY AND INTERNAL CONSISTENCY



Inter-rater Reliability: Assessors were required to rate caregivers' difficulty on 15 different assessment areas using a 1 to 4 schema where 1 meant little/none difficulty, 2=some difficulty, 3=significant difficulty, 4=extreme difficulty. The Kappa statistic was used to interpret the strength of the agreement between Assessment A and Assessment B on each of the 15 areas. Due to the rare usage of the "extreme" code and in order to generate symmetric tables necessary

to compute a value for the Kappa statistical test, the cases which had been assigned 4 were recoded to the value 3. To understand the stability of the tool, the 15 assessment areas were examined by a series of variables measuring assessment conditions, caregiving context, and implementation issues. These variables were: assessors' prior knowledge of caregiver, assessors' experience doing home care assessments, assessors' professional background, presence of others during assessment, type of care receiver, geographic region, research site, number of days between Assessment A and Assessment B, assessors' familiarity with the tool, and caregivers language. In addition to the assessment areas, this same procedure was used to examine inter-rater reliability between key areas of concern which were pre-established for use by assessors. The user guide's 38 key areas of concern were recoded to facilitate analysis. Similar to the assessment areas, the Kappa statistic was used to interpret the strength of the agreement between Assessment A and Assessment B on each of the 18 areas and select issues were examined by the series of control variables.

Internal Consistency

T-test analysis was conducted to understand the association between the rating of the assessment areas and the identification of the key areas of concern. A comparison of the mean scores on each assessment area was examined in relation to each key area of concern. In conducting this statistical test, these data previously considered ordinal in nature are treated as interval. The assumption is made that the differences between the variables are quantitatively equal. If the distance between some (score=2) and significant (score=3) is different than between significant (score=3) and extreme (score=4), than this assumption is violated.

Limitations of Kappa

The Kappa statistic is the recognised measure to understand the strength of agreement between two observers or assessors. It provides statistical credibility that two assessors did not arrive at similar conclusions by chance and it takes into account where in the table the agreement lies. Several assumptions of Kappa, however, pose interpretation problems for these data. For example, Kappa assumes that one observer completes all the first interviews and another observer completes all the second interviews. The design of this research violates this assumption because it involves 40 different assessors with no overall consistency in terms of Assessment A and Assessment B. Further, the data from this research do not offer much variation across the four response categories to allow the Kappa to effectively demonstrate strength of agreement. For most assessment areas over 60% of the response is within the "None/little" category which in and of itself is positive in terms of measuring agreement. However, because the value of Kappa depends upon the proportion of subjects in each category the fact that only the majority of subjects fall in one cell poses interpretation problems for these data. In other words, Kappa considers agreement only and takes no account of the degree of disagreement – all disagreements are treated equally. A measure to correct for this weakness is applying weights to disagreements according to the magnitude of the discrepancy. To redress the disproportionate distribution of responses across the categories, weights were assigned to the diagonal (see Altman, 1991 for info on this methodology). A weight of .5 was assigned to values which were +/- 1 in the difference, a weight of 1.0 was assigned when the difference was +/- 2. Thus, the higher the score the greater the discrepancy.

4.3.3. Qualitative validation of the tools

To validate the assessment tool, focus groups with participating assessors and interviews with supervisory personnel were held at each site. Each focus group and interview was designed to capture feedback on the content of the tool, usefulness and appropriateness of the tool, possible reasons for discrepancies in inter-rater reliability, as well as to discuss whether the tool had met its objectives. Interviews were also held with intake personnel in two agencies which had provided us with the majority of the screening tools to again capture feedback on the content of the tool, its usefulness and appropriateness and whether it met our objectives.

5. Description of project results

This section will present the results concerning the two tools separately. In the case of this research, the results are the tools themselves, the analysis of their validation and the transferability of the implementation process.

5.1. Development and validation of the screening tool

5.1.1. Design of the screening tool

The Caregiver Risk Screen has been developed to establish a more systematic method of determining the situation of family caregivers. The purpose of the screening tool is to assess the level at which a caregiver's physical and/or mental well-being is at risk and whether the care being provided is adequate. A level of risk is determined to establish the urgency of intervention. Potential outcomes which may result from delayed intervention could be abuse or neglect of the care receiver, family breakdown, or a change in the caregiving situation.

The test version of the screening tool contains two parts: the first collects information on socio-demographic characteristics and the context of the caregiving situation, and the second constitutes the tool itself. It consists of 12 statements regarding the caregiving situation about which caregivers are asked to express their level of agreement on a four point scale (totally disagree, somewhat disagree, somewhat agree, totally agree). A copy of the test version in both languages can be found in Appendix A.

5.1.2. Description of the sample

Before proceeding to a presentation of the results of the validation study an analysis of the profiles of the study participants will be presented.

Eighty-two percent of the caregivers were female and 18 per cent were males. Ages varied between 24 and 89 years with an average of 60 years. For almost, two thirds the primary language was English only (60.5%) for one third French (35.5%) and four percent were bilingual. Approximately one third of the caregivers came from a rural region and two thirds from an urban. In terms of their relationships to the care receivers 27.6% were spouses, in 36.8% cases the care receiver was the mother and the other third were fathers, mothers in law, fathers in law, sisters in law, child, aunt, uncle, friend or neighbours.

Approximately two thirds of the care receivers were female and one third males. In more than half of the cases (52.6%) the care receiver was living with the caregiver and more than half of the care receivers were cognitively impaired (57%). In terms of the intensity of caregiving, 43.4% said they did it all the time. The length of helping varied greatly from between 2 months and 32 years.

5.1.3. Internal consistency

The internal consistency of the screening tool is very strong. The Alpha Cronbach measure calculated for the 12 items is 0.88.

TABLE 1. RESPONSES TO THE ITEMS OF THE SCREENING TOOL

#	Question	Mean (SD)	Scale Mean if Item Deleted	Corrected Item- Total Correlation	Alpha if Item Deleted
1	Negative effects on physical health.	1.72 (1.16)	12.47	0.579	0.872
2	Not coping well	1.41 (1.07)	12.76	0.662	0.867

3	Cut off from social activities	1.82 (1.26)	12.27	0.649	0.868
4	Strain on family relationships	1.21 (1.24)	12.99	0.539	0.875
5	Unable to continue	0.89 (1.10)	13.27	0.661	0.867
6	Strain on CG/CR relationship	1.08 (1.20)	13.11	0.547	0.874
7	No longer worth the effort	0.37 (0.83)	13.80	0.497	0.877
8	Not a minutes break	1.00 (1.12)	13.17	0.673	0.866
9	More share of caring compared to others	2.22 (1.16)	11.96	0.301	0.888
10	Feel depressed	1.21 (1.21)	12.97	0.652	0.867
11	Losing control of life	0.87 (1.06)	13.31	0.744	0.863
12	Increased intake of alcohol, drugs, cigarettes	0.43 (0.97)	13.73	0.472	0.878

5.1.4. External consistency

The Caregiver Burden Screen is composed of two parts for which the response scales are different. The first part of the instrument has been used in studies of English-speaking and French-speaking populations. The alphas obtained for both parts of the tool are 0.87 for the first part and 0.75 for the second part indicating that the tool has a good internal consistency.

The correlations have been calculated between the screening tool and the Caregiver Burden Screen for the first section separately, the second section separately and for the total Caregiver Burden Screen Instrument. The next table shows the results of the correlations.

TABLE 2. CORRELATIONS BETWEEN THE SCREENING AND THE VALIDATION TOOLS

Pairs in comparison		Correlation Coefficient*	Significance
Screening tool	C B S (part 1)	0.87 Pearson	p < 0.005
Screening tool	C B S (part 2)	0,57 Spearman's rho	p < 0.005
Screening tool	C B S (parts 1 & 2 combined)	0.83 Pearson	p < 0.005
C B S (part 1)	C B S (part 2)	0.74 Spearman's rho	p < 0.005

* *Statistic named (Pearson Correlation Coefficient or Spearman's rho)*

All the correlations are high and significant, showing there is a good relationship between the Caregiver Risk Screen and the Caregiver Burden Screen.

5.1.5. Other variables

- Consistency regarding language of the two instruments

Even though the numbers of interviews were not sufficient for us to analyse the French version of the tool separately for the validation (only 25 respondents were uniquely French-speaking and 46 were uniquely English-speaking) we verified whether or not the responses to the items and the total instruments were similar or showed any significant differences. The Wilcoxon test for non-parametric data was applied to each item to compare the English and the French versions. The results of the analysis indicate that 9 out of the 12 items did not show any significant difference. In view of the difference regarding items 1, 3, 8 of the tool, since we did not find any significant differences regarding the translation of the items from English to French, we tested to see whether there may be differences between the English and French versions. Variance analyses were made on the mean global score to verify if the English version and the French version showed any significant differences. The results indicate that the English version (mean = 15,0) had a significant higher average mean than the French version (mean 11.0) ($f(1.69) = 3.90$, $p < 0.05$). In order to find out whether this difference was due to language of the questionnaire, since only Quebec interviewees were French-speaking, we then compared the means of the two language versions but only for Quebec. This time the variance analyses indicated no significant difference ($f(1.48) = 0.25$, $p = .87$) between the French version (mean = 11.3) and the English version (mean = 11.6). We can hypothesise therefore that the province may be a more important factor in explaining the differences than the different language versions used. However because of the small numbers we could not confirm this and future researchers should look into it further.

- Cognitive Impairment

It was interesting to note in the analyses that there was a significant relationship between those caregivers caring for a person suffering from cognitive impairment and two (1 & 11) of the items in the screening tool: that caregiving has negative effects on physical health and experiencing loss of control over their lives. It is thus important to note the high percentage of caregivers in the study (57%) caring for a person suffering from cognitive impairment.

- Cut off point

Unfortunately because this is a new tool and we only had a small number of valid participants in the study (76), we were unable to note a specific point which would denote caregivers who are at risk to their general physical and mental well being. However, we were able to distinguish a distinct group of 13 caregivers with scores of 23 or more points, while 55 respondents scored less than 14. Further use of the tool is necessary to confirm whether 23 is a good cut off point.

- Length of caregiving

There was a slight difference between those caregivers who were at high risk, who were giving care for a shorter length of time than those who were caregiving over a longer time. The caregivers caring the longest appeared to be at slightly less risk. We could explain this by hypothesising that they may become resigned to their difficulties or accept them over time and also that new caregivers are still undergoing the shock of adaptation to their new situation.

- Age and gender

There were varied age ranges between the caregivers in this study (24-89 years). When the caregivers' ages were arranged in three categories (24-50, 51-65, 66+), there was a slight upward sloping trend indicating that caregivers who were older were more at risk. There were no significant differences in terms of gender, although this finding is cautionary given the small number of men in our sample.

5.1.6. Discussion of results

In the external consistency measures all of the correlations are high and the Alphas significant showing a good match between the validation instrument and the screening tool. Regarding the internal consistency of the screening tool, all the items are significant.

The Alpha co-efficient is very strong and remains strong if any individual item is deleted consequently we should keep all of its twelve items. We note higher scores for items 1, 3 and 9 and lower scores for items 7 and 12 even though all items are significant. Caregivers were most likely to disagree that their caregiving efforts are not worth while and that they have increased their alcohol and/or drug intake in the past month. This concurs with the literature that even though caregiving is burdensome caregivers still feel it is worth while. Also, they may be influenced by socially desirable responses. As well, one admits that caregiving is not worth while only when one is at the end of one's rope, which is likely the case of a minority. We also note that caregivers tend to agree that caregiving has negative effects on their physical health, cuts them off from social activities and does not give them a minute's break. We do not have a general profile of risk emerging containing a few elements, as different caregivers experience different elements of difficulty. This concurs with research which observe that each caregiving experience is unique and individual (Lesemann & Chaume, 1989).

In terms of the language of the versions of the screening tool there seems to be a slight difference between how Quebec caregivers answered three of the items versus those from Nova Scotia. This could be due to various factors but we cannot hypothesise from this small study and a larger study should be done in the future under strict rules which predetermine the choice of caregivers. In general the other 9 factors were scored the same way in both versions of the tool.

5.1.7. How the tool affected the elements of the HTF Evaluation

In focus groups with intake workers and in the validation study, the following evaluative elements emerged.

1. **Quality of services:** Screeners were able to gain precise self-reported perceptions of the caregivers concerns and levels of distress. They particularly noted the importance of questions relating to depression and strain on family relationships.
2. **Access to health services and integration of a new group of stakeholders:** The tool focuses on caregivers and their situation and thus will help practitioners to prioritise those at risk, which should improve access to services for caregivers and facilitate giving appropriate help. Workers in some agencies in Quebec found it very difficult to use the screening tool during the testing phase because of the organisation of their intake process, leading us to conclude that efforts need to be made to organise their intake procedures in a such way that caregivers can be screened for risk since this would better target interventions. As well, we were surprised that in many cases caregivers do not telephone agencies for help. This has been already pointed out in former studies (Paquet, 1999). Thus, caregivers need to be more sensitised to what agencies can offer early on in their caregiving experience and encouraged to ask for help.

3. **The tool standardises and objectifies screened appreciation** of caregiver situations and targets caregivers at risk. The tool could be used in other agencies such as hospitals, or in family doctors' offices, sensitising both professionals to caregiver distress and caregivers to availability of services and the need to ask for help.
4. **Health impacts:** The tool works for a variety of caregiver situations. Sometimes, caregivers identified themselves as, for example, being depressed, when the intake worker had not previously picked up on health issues. Caregivers caring for a person suffering from cognitive impairment are at risk regarding their physical health and their perceptions of control over their lives. Since caregivers who continue over a long time may become resigned to their job, it would be important to be able to detect caregivers at risk as soon as possible.
5. **Cost-effectiveness:** The intake workers felt the questions were appropriate and improved the efficiency of their intake interview. If intake workers use such a tool to systematically target caregivers at risk they could target services (should such services exist) in a more cost effective way.

It is also important to note that this is the only screening tool which has such a variety of diverse elements which contribute to a portrait of risk to the caregiver's physical and mental health. It therefore seems pertinent to recommend it to other agencies and provinces to use and test further. We can conclude that this is a valid instrument which can predict caregivers at risk for their physical and mental health on a broader level than other instruments which usually are very long or measure only one or two specific dimensions of risk, such as depression

5.2. Development and validation of the assessment tool

5.2.1. Introduction

This section provides an overview of the design of the assessment tool and the results of analysis to answer two research objectives: 1) to determine inter-rater reliability between Assessments A and B and 2) to assess internal consistency within each assessment as outlined in detail in Section 4.3.2. Further, analysis is completed in order to understand under what conditions and in what situations the tool may function better both in terms of inter-rater reliability and internal consistency.

5.2.2. Design of the assessment tool

Following the original proposal for the project, the assessment tool produced for testing was designed to collect information on many different areas of a caregiver's situation, and to pinpoint from this information the key areas of difficulty being experienced and the types of services or support that would best assist the caregiver. It was intended to collect information from the caregiver's perspective and enable the assessor to contribute her/his perspective when summarising the key concerns for the situation.

Maddock, Kilner & Isam (1998) identify a need for a blend of assessor input as well as a self-assessment by the caregiver in a caregiver-directed assessment tool. From the validated tools search it was also found that the caregiver assessment tool should contain items that account for objective and subjective views of caregiver burden, in order to better discern between the caregiver's and assessor's interpretation of needs.

The order of the sections was arranged as an attempt to help the assessor achieve rapport with the caregiver, help the caregiver develop some comfort with the questions being asked, and close the interview in an effective manner that would not leave the caregiver feeling uncomfortable. During the informal pretesting it was found that the order of the sections left many caregivers feeling stressed; and a different ordering was suggested to place emotional health and family issues within the middle of the assessment. These comments were echoed by the Advisory Committee.

The sections were thus arranged to begin with task-oriented questions and less sensitive areas, then open to more sensitive, introspective questions, and end with discussion on more concrete issues such as planning and services. The final questions in the assessment were also designed to allow the caregiver to contribute additional information that may not have been covered and provide feedback on the interview process. Following the interview the assessors were instructed to complete a summary section to indicate levels of difficulty in 15 identified areas and indicate the key concerns of the situation. This section also enables the assessor to consider and record the types of services that

would best help the situation. It is in this section that the assessor is able to incorporate her/his perspective and provide a rationale for the services recommended. A copy of the test version in both languages may be found in Appendix B.

5.2.3. Description of the sample

Caregiving Situation

Prior to in-depth analysis of the research sample, it is important to review the unique nature of the sample as caregivers whose care receivers are clients of provincial home care programs. Consequently the caregiving situations described in this sample are generally requiring more intense care than population-based surveys of caregiving situation such as the 1996 General Social Survey (see Keating et al., 1999)

There are 168 caregivers in our sample (see Table J-24 for general demographic information). The description of caregivers is typical in that most were women and either a child or a spouse of the caregiver. Where the sample is somewhat unusual is in the diversity of caregiving situations and the extent of the caregiving work. There are six cases where parents are caring for their disabled children. Another one-third of the sample are persons carrying for someone with dementia but the majority of situations are older persons (average age 78) with at least one or two health problems . Over three-quarters of the caregivers and care receivers co-resided (78%), and almost half of the caregivers had been caregiving for over five years (mean = 7.6 years).

Considerable variations emerged in response to basic questions between Assessments A and B. For example, the caregivers were asked to indicate whether they would consider their caregiving responsibilities as: 24 hours a day, full-time, part-time, or occasional (see Figure J-2 in Appendix J). Interestingly, there was significant variation in the responses concerning caregiving responsibilities between Assessment A and Assessment B with 35% of caregivers giving different responses. This may be assessors recoding information inaccurately, lack of clarity in meanings or the impact of someone else in the room, such as the care receiver. Nevertheless, the responses are an indication of the extensive level of care provided by this sample of caregivers. Using Assessment A as a guide, 54% of caregivers indicated they provided care 24 hours a day, and 27% indicated that they provided care full-time.

Other examples of variation in responses between Assessments A and B were additional responsibilities, including numbr of children cared for (Table J-3 in Appendix J), and what changes they would consider in the future (Table J-4 in Appendix J).

The discrepancies noted in the information that caregivers gave the assessor at time one and time two may simply reflect a different perspective on a different day. However, researchers were interested to investigate whether there were patterns in external variables that may help explain incongruencies (see Tables J-5 and J-6 in Appendix J).

5.2.4. Inter-rater reliability

5.2.4.1. Assessment Areas

Based on the information received throughout the assessment, assessors were asked to rate the amount of difficulty being experienced by the caregiver on 15 assessment areas. Table 3 demonstrates that caregivers in this study were experiencing difficulty in all 15 assessment areas but at varying levels of difficulty. For example, these caregivers were having the least amount of difficulty with formal services, housing and financial costs. On the other hand, areas which caregivers were experiencing more difficulty with were supervision and support, physical health, mental health and planning for the future. This cursory look at the data is helpful in understanding the forthcoming results of the inter-rater reliability as it demonstrates the lack of variance across the categories.

TABLE 3. ASSESSORS' RATING OF DIFFICULTY ON 15 ASSESSMENT AREAS (N=163)

<u>Little/none</u>	<u>Some</u>	<u>Significant</u>	<u>Extreme</u>
--------------------	-------------	--------------------	----------------

	A	B	A	B	A	B	A	B
Physical Care	57%	60%	33%	27%	11%	10%		3%
Housework	61%	61%	33%	28%	6%	11%	1%	1%
Supervision/Support	34%	36%	37%	39%	25%	23%	4%	1%
Coordination	60%	61%	30%	27%	10%	11%	1%	1%
Help Received	56%	55%	34%	31%	10%	12%		2%
Formal Services	77%	85%	20%	10%	3%	4%	1%	1%
Housing	72%	81%	22%	12%	5%	7%		
Juggling Responsibilities	50%	56%	37%	34%	13%	10%	1%	1%
Financial Costs	74%	79%	20%	13%	6%	7%	1%	
Physical Health	47%	47%	36%	37%	17%	18%	1%	2%
Mental Health	38%	37%	39%	37%	21%	24%	2%	3%
Relationship to CR	53%	48%	33%	37%	14%	13%		2%
Relationship to Family	58%	65%	31%	26%	10%	8%	1%	1%
Crisis Planning	50%	48%	34%	39%	15%	11%	1%	2%
Future Planning	45%	39%	35%	40%	18%	18%	2%	3%

Table 4 presents the results of the bi-variate analysis conducted to measure agreement between A and B assessments. The extent of agreement between the two assessment periods across the 15 areas ranges from 45% to 79% with 13 areas achieving 50% agreement or higher. While the amount of agreement is favourable, the strength of the agreement for all assessment areas is below the moderate range (for interpretation guidelines, see Altman, 1991). This finding is largely due to the lack of distribution across the categories.

Table 4. Assessment Areas (N=168)

Assessment Area - difficulties	%	Kappa
1. Caregiving Tasks – physical/nursing care	59%	.260***
2. Caregiving Tasks – household work	54%	.142*
3. Caregiving Tasks – supervision/support	45%	.170**
4. Caregiving Tasks – coordination	53%	.154*
5. Caregiving Tasks – help received from others (formal & informal)	50%	.129*
6. Relationship with Formal Service Providers	70%	.116
7. Housing	67%	.120*
8. Juggling Responsibilities	52%	.166*
9. Financial Costs	70%	.277***
10. Personal Health – physical health	54	.274***
11. Personal Health – mental health	45%	.154**
12. Relationships – with care receiver	58%	.312***
13. Relationships – with family	61%	.261***
14. Planning – crises	79%	.141
15. Planning – future	71%	.074

Note: * $p < .05$; ** $p < .01$; *** $p < .001$.

Agreement is evident in the areas of a more practical/instrumental nature such as: physical/nursing care and financial costs as well as in areas addressing relations with the care receiver and the family. Other areas demonstrating strong frequency of agreement include relationship with formal services, housing, planning for crises and planning for the future. These areas, however, do not achieve a moderate Kappa value or statistically significant differences.

Agreement between the two assessment periods differs most in the areas of supervision and support, and caregiver's mental health. If the assessor rated the assessment area to be None/Little Difficulty, they were asked to indicate whether or not this was an area of potential difficulty. For this subset of cases, the *extent* of agreement percent improved in almost every assessment area. The *strength* of the agreement (Kappa) remains weak and often in a negative direction due to minimal variance between the groups and these data yielding a 2 x 2 table (see Table J-7 in Appendix). It should also be noted that assessors used this question in an inconsistent way which was cleaned at the point of data entry. They commonly coded Potential Difficulty with response categories other than None/Little Difficulty which was contrary to instructions.

To redress the disproportionate distribution of responses across the categories, weights were assigned to the diagonal. Results from this analysis suggest that the weighting offers little improvement to Kappa values. These results indicate that the majority of difference is between None/Little Difficulty and Some Difficulty, the two lowest categories.

The inter-rater reliability of the assessment tool was further examined by select variables to understand under what conditions and in what situations the tool may function better. In other words, is the extent of agreement likely to improve for the overall tool, or particular assessment areas, when controlling for conditions such as: assessors'

familiarity with the caregiver prior to the assessment, assessors' length of time doing home care assessments, assessors' professional background and who else was/not present during assessment (see Tables J-8 to J-17 in Appendix J for tables of 15 assessment areas by each control variable). Table 5 (see next page) provides a synthesis of the results of bi-variate analyses examining these factors. The letter "C" indicates the extent and/or strength of agreement *changes* from the TOTAL (ie. +/- 10% and/or +/- 1 band for value of Kappa), while the "—" indicates the statistics remain *similar* to TOTAL.

Of the ten control variables examined, five result in significant change to the inter-rater reliability of the tool. These are: assessors' professional background, presence of others during assessment, type of care receiver, number of days between Assessments A and B, and assessors' familiarity with the tool. While either the frequency of agreement or strength of agreement changes under these conditions for select assessment areas, the changes do not occur in any consistent pattern. Thus, we are unable to generalise that inter-rater reliability improves/or not as a result of any of these factors. For example, when considering the professional background of assessments, a few assessment areas improve when the assessors are both nurses while in others it does so when one assessor is a nurse and the other a social worker. Further, when considering the affect of having someone present during the assessment, even in situations where someone was present at one assessment and not the other, there is not a consistent pattern of agreement increasing or decreasing. For some individual assessment areas, agreement increases while for others it decreases. Without a doubt, however, the presence of others during the assessment does appear to matter and makes the assessment process more volatile.

Two areas of assessment where agreement for the whole sample is less than favourable - Supervision/Support and Mental Health - do not consistently improve their performance when external factors are considered. However, Mental Health appears influenced by variables describing assessment conditions and caregiving context. Supervision and Support is influenced by variables describing assessment conditions, caregiving context and implementation issues. This would suggest that the feeder questions for these two areas need to be examined to understand consistency of the information recorded. Were there issues with the clarity of questions or was it that different information was offered by the caregiver. If the latter, there is little more that can be done to the tool except stress preferred conditions for its administration. If there is a problem with the question in terms of clarity or intent, then further refinement to the questions should be made.

5.2.4.2. Key Areas of Concern

As part of the summation, assessors were required to identify 2 or 3 key areas of concern for each case. The most common key areas of concern were Respite care (just over half of the cases), the caregiver's Mental Health (about thirty percent of the cases) including grief and isolation (see Table 6). Relations with the care receiver and relations with other family members were also frequently identified as a key area of concern as were areas related to planning, either future or emergency planning. There are only 6 cases where no areas of concern were identified in Assessment A.

TABLE 6. FREQUENCY OF IDENTIFIED KEY AREAS OF CONCERN (IN DESCENDING ORDER)

Key Area of Concern	A Assessor % (N)	B Assessor % (N)
Respite	51% (85)	47% (79)
Mental Health	29% (49)	26% (44)
Relations with CR	24% (41)	21% (35)
Future Planning	23% (38)	24% (40)
Relations with Family	17% (28)	19% (32)
Emergency Planning	16% (27)	14% (24)
Physical Health	15% (25)	14% (23)
Basic ADLs	15% (25)	13% (22)
Emotional Support for CR	9% (15)	8% (14)
Coordination of Services	8% (14)	5% (8)
Finances	7% (11)	3% (5)
Equipment	5% (8)	3% (5)
Information	5% (8)	5% (8)
No Concern	4% (6)	87% (146)
Housing	4% (6)	7% (12)
Transportation	3% (5)	6% (10)
Relations with Services	2% (4)	4% (7)
Other	2% (3)	4% (7)
Language	1% (1)	1% (1)

The key areas of concern are tested for inter-rater reliability. In other words, when assessing the bottom line of the caregiving situation, does the assessment process support two assessors coming to comparable conclusions about the situation.

Table 7 demonstrates the amount and strength of agreement between Assessment A and Assessment B when making final conclusions about the caregiving situation. The amount of agreement ranges from 65% to 99% with several Kappa values reaching the moderate range. These results are more favourable than those of the assessment areas. The strength of agreement varies and has more to do with cell size and distribution. These data are categorised into Yes/No groups which further reduces response categories. Three areas appear to be the most problematic in terms of their response pattern. Future Planning, Mental Health and Respite demonstrate the lowest agreement. This finding is consistent with that of the previous section in that Mental Health and Supervision/Support were two assessment areas with lowest agreement and greatest fluctuation when controlled for external variables.

TABLE 7. KEY AREAS OF CONCERN (N=167)

Key Area of Concern	%	Kappa
1. No Concern	96%	.342***
2. Relations with CR	75%	.286***
3. Finances	92%	0.087
4. Emergency Planning	79%	.191*
5. Emotional Support for CR	87%	.207**
6. Equipment	95%	.281***
7. Relations with Family	83%	.432***
8. Future Planning	65%	0.005
9. Mental Health	67%	.181*
10. Physical Health	79%	0.124
11. Housing	93%	.300***
12. Information	90%	-0.05
13. Language	99%	.
14. Respite	69%	.389***
15. Coordination of Services	90%	.226**
16. Relations with Services	95%	.156*
17. Basic ADLs	79%	0.134
18. Transportation	96%	.514***
19. Other	95%	.179*

Note: * $p < .05$; ** $p < .01$; *** $p < .001$. The “.” indicates that Kappa is missing due to asymmetrical table.

The areas which yielded least favourable performance were further examined by the 10 control variables to understand if agreement will increase, decrease or remain the same under specific conditions or contexts. These areas were Future Planning, Mental Health and Respite (see Tables J-18 to J-20 in Appendix J).

Future Planning does not consistently increase or decrease under any conditions. However, both Mental Health and Respite are influenced by specific factors. For example, agreement improves for Mental Health when both assessors have similar home care assessment experience, are both nurses, and both had experience with our tool. Further, performance improves when someone is present at both assessments, the caregiver speaks English at home and the agency was rural Nova Scotia. Similar factors influence the performance of respite. For example, someone present at both, assessors being experienced with the tool and caregivers who speak English at home. It is recommended that the areas informing these sections be reviewed to determine if specific questions appear problematic.

5.2.5. Internal consistency

This section provides results of a series of t-tests completed to perform a means comparison with each area of difficulty to indicate the areas which had higher levels of difficulty among cases where a key area of concern was identified. For example, among cases where respite was identified as a key concern, what corresponding areas of difficulty had significantly higher levels of difficulty than cases where respite was not identified.

Table J-21 (see Appendix J) reports the mean scores of level of difficulty within each area of concern. Generally, the areas where the level of difficulty scored higher were consistent with the types of key areas of concern raised. In other words there appears to be a high degree of internal consistency within the summary sheet for Assessment A and Assessment B. For example, for Respite Care (the most frequently identified key area of concern), the average score was significantly different for supervision and support and housework caregiving tasks. Another variable, Juggling Responsibility approached significance for Respite Care as a key area of concern. Data from Assessment B (see Table J-22 in Appendix J) reveal similar findings.

In cases where Mental Health of the caregiver was identified as a key area of concern, the level of difficulty with Mental Health as an assessment area was significant. In fact, the data indicate that the scores of the areas of concern the areas of difficulty corresponded closely to the construct being measured by the key area of concern. In other words, if an area was identified, it is likely based on high scores in the level of difficulty. In a couple of instances, it is clear that more than one variable is significant although even in these situation, the areas of difficulty are reasonable to expect.

5.2.6. Discussion

The results of the inter-rater reliability and internal consistency tests suggest that, for the most part, this comprehensive tool is a valid and reliable instrument to understand caregivers' needs and situations. A reasonable level of agreement between Assessments A and B exists between the 15 assessment areas and the 18 key areas of concern. Furthermore, the test for internal consistency indicates that the scoring of assessment areas informs related key areas of concern. While some variables influence the performance of the tool, there is not consistent significant improvement on any of the assessment areas when examining them by factors related to assessment conditions, caregiving context and implementation issues. This would suggest that for the most part the questions through the assessment tool appropriately inform the summation exercise at the conclusion of the assessment. In addition, the Summary Sheet developed to act as a synopsis of the caregiver's situation appears to have a high degree of internal consistency between what was difficult for the caregiver and the areas of concern upon which a service plan should be based.

Assessors' ability to draw similar conclusions for 16 out of 18 key areas of concern is extremely favourable in view of the heterogeneity of the sample, the number of assessors involved, the range of assessors' background, and varying approaches to administration of the project across the sites. Specific criteria and research protocol were established for the data collection. However, despite efforts to minimise variation within the data collection process, this research was conducted in the field which cannot be totally controlled as it evolves through the process itself and is shaped by the experiences of the assessors and caregivers themselves. Of the 168 cases a sub-group was drawn which represented the ideal test conditions to understand inter-rater reliability. Interestingly, the frequency of agreement and strength of agreement showed little improvement on the 15 assessment areas.

The socio-political context in which this research was conducted presented many challenges for the assessors and researchers. These issues are discussed in detail in section 5.3.

There are a number of issues that warrant investigation. For example, further testing should be done on individuals caring for individuals under the age of 65 without dementia to determine the tool's relevancy to this population as this population was under-represented in this study. Moreover, given that a few areas of the tool report less agreement than desired, a review of the feeder questions that inform these areas would be helpful.

One criterion established for the study included that the assessment should be conducted in private with the caregiver. However, this was not the case and whether or not someone was present did result in fluctuation in the inter-rater

reliability amongst the 15 assessment areas. This is not surprising given the nature of some of the questions and whether a caregiver may or may not want to disclose key pieces of information to an assessor depending on who else is present. For the most part, assessors report that someone else present did not have an impact but the data contradict assessors' perception. While it is recommended that the caregiver be assessed in private, given the situation of the individual it is likely not always going to be the case. In some instances, it is noted that the caregiver was providing care during the assessment and was interrupted by numerous calls and visitors, surely distractions that would affect the quality of responses. Assessors therefore need to be mindful of how the presence of others will influence caregivers' responses to specific sections of the tool.

Another criterion established for the study was the desired length of time between Assessments A and B. Again, because of the many challenges faced by assessors and the caregivers, the desired time frame of within 7 working days was not always possible. While the tool will not likely undergo the same scrutiny in practice (ie. two assessors interviewing same caregiver), assessors using the tool should be mindful of the fact that the time of the day, day of the week, week of the month could influence caregivers' responses to specific sections of the tool.

The Kappa statistic was not as informing as desired for our purposes for several reasons. First, the research violated an assumption of the Kappa statistic in that more than one individual was involved with A and B assessments. Second, the fact that most response is concentrated in the Little/None category and that most discrepancy occurs between the first and second response category suggests that these assessors would benefit from clearer instructions as to the differentiation intended as well as ongoing review and consultation about the use of these categories. Because this exercise was intended to test the tool, including its instructions, it was not appropriate for assessors to discuss their rating with the researchers, their supervisor or other assessors. This would not be the preferred approach in practice.

A review of the assessors' comments to the question "Why did you rate it this way?" indicates that assessors completed the Potential Difficulty section inconsistently. In some cases, it was used with response categories other than "Little/None", with a notation that "if things don't change" this will be an issue for the caregiver. In view of this finding, the tool may benefit from clearer instructions or a different layout for this information.

Finally, one section of the assessment tool where results are problematic to interpret was caregivers' sense of planning - for crises and the future. This is an area of new enquiry which has proven to be very important as both emerge as commonly identified key areas of concern. Assessors' comments, however, suggest they had some difficulty in discerning the differences between planning for crises and planning for the future. Further, assessors' comments suggest that these questions were very troubling to caregivers which may be contributing to interpretation problems. Revision to the rating categories and/or feeder questions may be warranted to improve interpretation and agreement. Further, assessors need to be sensitive to the caregivers' reaction to these questions, especially if no concrete program/service is available to assist them.

5.3. How the assessment tool affected elements of the HTF Evaluation Framework

The key questions for the evaluation plan are:

- 1) has the project been able to construct and validate caregiver screening and assessment tools which are appropriate to the needs of caregivers and for use by service providers in home care agencies throughout Canada?
- 2) is the implementation process transferable to other agencies and settings throughout Canada

5.3.1. The quality of care

The question of the relation between the development of the assessment tool and the quality of care must be situated with regard to the objectives set out for the tool. These objectives included : 1) increasing practitioners' understanding and awareness of what it means to be a caregiver; 2) covering all the essential areas of concern to caregivers; 3) helping practitioners to quickly identify caregivers' issues; 4) enabling practitioners to identify key areas of concern for service planning.

Based on the opinions expressed in the focus groups with assessors, the interviews with administrators, comments gleaned from caregivers during the assessment, and our own analyses, we can advance that the tool increases worker understanding of all aspects of caregiving and enables them to identify key caregiver concerns rapidly. In other words, the tool meets the objectives set out by the research team, yet at the same time moves beyond these aims. The assessment tool was able to both achieve its functional aims of identifying key concerns and at the same time had a positive impact on assessors and caregivers. The tool changed assessors' attitudes, and occasionally their practice with caregivers, while for caregivers, as noted by both assessors and administrators, the tool gave them recognition and validated their concerns and everyday efforts.

In terms of HTF's evaluation framework, we would advance that the assessment tool has the potential to change levels of satisfaction with the quality of caregiver/provider relationship from both the provider's and the caregiver's point of view (which it did even within the framework of a simulated exercise), and that it will lead to changes in the technical appropriateness of intervention by informing practitioners of elements in the context of home care recipients which have been given little attention until now but which impact on the adequacy of interventions.

5.3.1.1. Objective 1: Increases understanding/awareness of what it means to be a caregiver

According to assessors, the research process resulted in an increased understanding/awareness of the concrete reality of what it means to be a caregiver on a daily basis. Many workers discussed participation in this project as a learning experience and spoke of the insights they gained about caregivers. Participation in the project provided workers access to caregivers perspectives. While many workers had heard about caregiver issues in conferences and training sessions, their understanding of these issues was different after meeting individual caregivers. Repeatedly throughout the research sites, workers discussed their shock or surprise upon discovering the widespread difficulties faced by caregivers and that for many caregiving was not a choice. In this sense, the project gave workers access to the meanings and everyday realities behind the facts of caregiving and gave them a different perspective on caregiver concerns.

As a nurse, I knew a little, but I thought the difficult cases were much more isolated.

In my case, I never thought it was so painful for caregivers.

I think I see caregivers' lives in a whole new light now... I now see more clearly how it's 24 hours a day."⁵

Workers also discussed how their increased awareness allowed them to understand the cumulative impact of caregiving on everyday life. This understanding allowed them to go beyond looking at symptoms to look at underlying contributing factors. As such, the content of the tool allowed workers to move beyond their prior understanding of caregivers as 'burdened' to understand contributing factors and everyday impacts. In the following quotes, workers discuss how the tool enabled them to get a better grasp on underlying family dynamics and the impacts of caregiving on the different aspects of caregivers' lives.

No, it's not the same without the tool. I might know that someone else has a tumor but I don't know how it impacts on everything. I might not realise what going out to work means for the whole organisation with the... I mean I was aware of it, but not in the same...

The relationship with the family, the kids and the system. And you found out there were more issues with other family members, maybe not related to the care receiver, but to the caregiver themselves, which added responsibilities.

Discussions of increased awareness and understanding of the complexity and multiple impacts of caregiving raise questions about the caregivers current status in relation to service, and how caregivers may be integrated into practice.

⁵ Quotes taken from interviews held in French have been translated to English by the authors.

5.3.1.2. Objectives 2 & 4: Identifies caregiver issues and key concerns

Most workers found the tool to be a comprehensive way to gather new information about caregiver needs/concerns because of its depth and thoroughness and the fact that it alone is aimed at the caregiver.

I think you may find that the caregivers are more apt to drop their guard and share when the focus is on them as opposed to being fully on the client because the questions are geared like that in our Home Care Assessment.

In some of the situations. I shouldn't say with all of them but in some of them. There was a few that you didn't realise the other half of what was going on with the caregiver. Things that they told you that never would normally come up just with your client assessment.

5.3.1.3. Objective 3: Quickly identified needs

Sections 5.3.1.3, 5.3.1.4, and 5.3.1.5 address the HTF question of changes in technical appropriateness of intervention.

In addition to gaining understanding and awareness of key issues and concerns, many assessors felt the tool provided the means to gain a rapid assessment or quick identification of needs. Workers indicated that probably over time they would get similar information, but it would take them much longer to do so. This tool was a relatively concise way to gain an in-depth view of the situation. Particularly useful was the direct manner in which questions were asked. However, this appreciation is mitigated by the fact that many assessors found the tool to be very long and the average evaluation took 90 minutes, as noted in their written comments.

Workers have very limited time and don't want to be asking a lot of unnecessary questions.

Found questionnaire much too long.

However, some workers questioned their tendency to want to reduce evaluations to the filling out of statistical forms.

It might be two three-hour sessions. But that's another thing this tool told me is that I've been lulled into the idea that I need to get in and out of those houses as quickly as possible, do my assessment in black and white format and get out. And my heart tells me I shouldn't be doing that. And this reinforced that. You need to respect the individuals and they deserve separate times.

It should be pointed out that the assessors were in their natural setting but constrained to operate as part of a research team with a specific and rigorous manner of doing the assessment. If the tool were to be integrated into daily home care assessment practice there would be more possibility of adapting it to specific situations, and in particular to conducting it over more than one visit.

One particular site as a whole had a generally negative reaction to the tool. Even at the end of the project no one on this team felt comfortable with using the tool. Reasons for discomfort varied from the tool being too detailed, too repetitious and annoying, to the fact that within an hour using your interview and assessment skills you should be able to get the same information, indicating that there was no use for the tool. One worker felt that in two cases, after the assessment, she had no idea of what was going on. This group did however, indicate that the tool clearly identified the need for respite. In another site, one experienced worker felt the tool did not permit identification of anything new except an understanding of time constraints and crisis-based reactions. However, all other workers from the seven other agencies were unanimous in their positive assessment of the tool and its strengths in helping them more and fully understand caregivers' situations.

Thus, despite the one site which had difficulty adjusting to the tool, we can conclude that, in general, the assessment tool has great potential for improving the quality of services to caregivers, and indirectly, to care recipients. Within the framework of the project, workers gained new awareness which led to more empathetic understanding. Several

administrators pointed out that this is the first systematic evaluation of caregivers which has ever taken place and that should the assessment tool be implemented it will have major repercussions on the agency-caregiver relationship and the development of services for caregivers.

5.3.1.4. Objective 4: Allows for the development of an efficient service plan

Not only did the tool provide an effective means to gather new, thorough and in-depth information, but workers discussed the way the tool helped them to plan interventions. Workers found that using the tool they could move from the identification of caregiver concerns to a summary of principle issues and difficulties. As we saw in section 5.2.4.1 on the validation of the assessment tool, inter-judge reliability concerning the level of difficulty for each of the 15 items of the summary page was not high. However, assessors had a high degree of reliability in identifying the same major areas of concerns which demonstrates that the assessment tool, in a relatively short period of time, allows two assessors to come to the same understanding of what is of key concern in a specific situation, in most cases. Access to knowledge of key issues and concerns moves workers one step closer to responding more appropriately to needs.

You'd be looking for things that you normally would not be looking for. So it might be more efficient in that way. You might get a better picture of the situation, and the services that you put in would be more efficient.

5.3.1.5. Beyond our objectives: Long-lasting impacts of the tool

Many assessors felt that the impacts of this research will extend beyond the study period. Workers reflected on the ways their new sensitisation by the project impacted on their relationship with caregivers, how they had become more empathetic and sensitive.

But it really brought a lot of insight for me. And I told some of the people I work with. I said, "It's amazing, but I'm so much more sensitive to caregivers," not that I wasn't, but so much more so.

I had the facts, but I didn't have the explanation. I didn't have the context. And I feel that that greatly influences our way of intervening. Because, as I said earlier, there was one caregiver who before I found was almost inadequate in his role. After the assessment with the tool, I might still arrive at that conclusion but now I have elements which allow me to understand what's going on, which will influence the way I intervene.

Many workers also indicated that their experience of using the tool will have long-lasting impacts on their relationships with caregivers who they will no longer see as resources or as peripheral to their intervention. Rather, they now conceptualise them as partners to be included in determining the care recipient's service plan and as potential clients having their own service and resource needs. They proposed several ways that they would intervene differently in the future, such as: including the caregiver in the care-receiver plan; not taking the caregiver for granted (i.e., as a mere resource); conducting a separate interview with the caregiver; creating a stronger relationship with the caregiver. Workers discussed how they now understand that the caregivers have limits and will think twice before judging the situation or assigning responsibilities.

I feel, in my case, that I will be including them much more in my "plan d'intervention". As a beginning, I would do my multiclientèle evaluation, but I would definitely do a separate interview with the caregiver.

I always said that I wasn't someone who was judgmental, but I think I'm going to be even less so. When you see the care recipient often, when you're constantly with the person that you help, you lose your patience. But, as a nurse you go maybe once a week. And I'd often come back and say: He isn't very patient with his mother. But in the future, I think I'm going to hold my tongue more often.

However workers were concerned about how the caregiver would fit into the current mandate of service. They discussed the need to expand the notion of the client to include the caregiver, to expand the mandate and the necessity to provide resources to caregivers.

Because my focus is always on the client, and if there's a caregiver, I've either taken that person for granted: "Good, you've got caregiving, I don't have to give you as much this or as much that." I mean, I have a relationship with the caregiver, but no focus on that caregiver.

There was a strong message of awareness and several examples of the impact on practice, however workers indicated that impacts and modifications were subject to policy constraints. These constraints included time restraints, policies which do not recognise the caregiver and a lack of resources. Workers said despite new understanding and time they had with caregivers, they are always constrained by policy. So as long as they do not have the time and resources to do this kind of evaluation, they cannot do it.

5.3.2. How does the tool affect access to health services?

Some workers indicated that the tool worked well within the context of their practice; the new information or a better understanding of caregiver issues they obtained led to changes in their understanding of the service and resource needs of caregivers. When these services and resources are available this will lead (and did lead in some cases) to a better access to services for caregivers. In this section we will examine the immediate impacts of the tool on some workers' practice in terms of increasing caregivers' access to services, although these changes go beyond the scope of the objectives of this project which were to test and validate the tools. Based on their experience, many workers and administrators have to come to the conclusion that home care programs must change their mandate to include caregivers among their clients, raising the issue of available monetary and human resources to meet the needs of this new client group.

It was evident through discussions with assessors and administrators that participation in this research project had several impacts on practice and raised, in a dramatic way, the current lack of access caregivers have to evaluations and services. The assessment tool aided caregivers, practitioners and administrators alike to identify the quasi-absence of resources aimed at modifying caregivers' situations and those services and resources which would be essential to develop to meet the needs of caregivers. Impacts during the study included the validation of intervention strategies, (discussed further in answer to question 3 on integration of new stakeholders) and modification of service plans during the study period to initiate or increase services to care recipients and care givers thus giving them increased access to existing services.

5.3.2.1. Changes in the way services are delivered which took place during the study and led to increased access to services

One impact of the tool seemed to be at the level of modifying service plans to take into account the new understanding of the caregivers' situation despite the fact that there were clear guidelines indicating how and when workers could use the information gathered through the research process to make services changes. In all agencies, workers intervened in problematic cases they uncovered. There were a few examples given where workers uncovered emergency situations and sent services in immediately. Other interventions included adjusting services, conducting re-assessments, making referrals for counseling or medical interventions or requests for additional services such as respite.

I didn't respect the rule which was stated for the research, that is that because we were assessing their situation they shouldn't expect any extra services. I took advantage of the assessment. Honestly, I took advantage to re-examine the organisation of care in the home. I said to myself, "Strike while the iron is hot." I had information and there are some things which I readjusted, to the extent I was able to, of course, by using the means at my disposal.

5.3.2.2. *Changing the notion of client & health to assure that caregivers have access to services*

Current notions of the client would mean that caregivers remain excluded from services, while no or limited resources would mean that there would be no change to the practice with caregivers. Workers were extremely concerned that it is difficult to impossible to change practice considering current resources. After having participated in the research, many of the workers saw the need to change the mandate of service. Some workers stated that they consider the caregiver a client in their daily practice, while others indicated that seeing the client and caregiver in combination were complimentary, and wished that this was part of their everyday practice. One site specifically discussed the narrow focus on health and how health should be expanded to include the more global situation of care receivers and caregivers. It seems that the inclusion of the caregiver would result in more comprehensive service plan.

It's made me think of partnership as an option that we often ignore because we're busy and we have to put in services and I can't be bothered to go find my partners. But if we had more time, fewer clients, we could do a more ideal treatment plan.

This makes me realise that often we hear [when talking about caregivers' needs] "Oh yeah but that's not a health concern." [...] I'm not under valuing what we're doing but I think health should be doing it. ... because it impacts directly on the health of the care receiver and the caregiver. Our mandate is currently not focused on the caregiver... when it is, it's only task-related.

5.3.2.3. *Increased awareness of the lack of resources to meet caregiver needs*

Workers were not always able to modify their service plans in line with the results of the assessments, despite a clear identification of need because of the limited resources available to them.⁶ Thus, at the same time that workers became aware of the needs of caregivers, they also became aware of the lack of agency or community services and resources with which to meet these needs. The connection between identifying need and responding was agreed to in principle, yet would only lead to intervention should services become available. Many workers were so frustrated by this situation they were almost motivated to set up community resources by themselves.

It just made me feel I wanted to go home and start a support group. And a newsletter and volunteers to visit. I thought... it was I'm starting a day care, an adult day care.

So it taught me more of about what was lacking in the community because they were [constantly saying]: "That would be useful."

5.3.2.4. *Given the diversity of caregivers and caregiver situations, are the tools appropriate for ensuring access for all?*

- **General adaptability**

Once we have demonstrated that the tool works well to identify caregiver issues and the services required to meet their needs, the question of its adaptability to a variety of situations and groups must be posed. The majority of workers and administrators believe that the assessment tool is appropriate for use in diverse settings and situations, and that it is adapted to various ethno-racial and cultural groups, as well as urban and rural populations. Specifically,

⁶ When asked directly "What kind of help do you [caregiver] think you need?", the top two responses were respite/day centre services and homemaker services. This finding concurs with that of a subsequent question where, from a pre-established list of 18 services/programs, caregivers were asked to indicate whether they would benefit from services even though they may not currently exist. Over 75% of caregivers identify respite/day centre, homemaker services, information services, help with long term care options and support for emergencies. This latter point is directly a result of the tool's questions as this is an area not previously investigated. Caregivers also identified the remaining 12 services to be of benefit to them, but at lesser frequency.

workers and administrators consider the tool to be appropriate for a wide variety of caregiving situations including caregivers to adults with mental health problems, physical or intellectual handicaps, and chronic diseases .

I found it adaptable. I had quite a variety and I had a couple of French, a couple of English, different ages. It was quite adaptable.

I can see how the tool is adaptable to the mental health sector. It seems to me it's a universal tool applicable across the country because caregivers' needs are the same.

However, we were not able to validate this subjective appreciation of the tool's adaptability to caregivers of non-elderly people with handicaps because we didn't have a large enough sample.

Two major concerns in relation to adaptability however include difficulties in comprehension for persons with little schooling, and the comprehension of persons for whom neither French nor English is their first language. Workers felt that simplified terminology would address these two concerns (see Appendix K) with recommendations for word changes.

- Rural setting

Workers in rural Nova Scotia discussed adaptability specifically in relation to the rural/urban contrast. In this sense, they felt that the tool was not only appropriate and adaptable for a rural population, but that the tool reflected distinct rural concerns such as distance and transportation. A key concern among rural practitioners however, was that few services are actually available in rural settings. In this sense, workers discussed that yes, the tool is adaptable, however they were concerned that few services meant that few caregivers would actually receive anything.

- Gender, class and level of care

Individual workers and administrators raised particular questions and concerns regarding gender, class, and level of care. Considering gender adaptability, one worker noted that it was more difficult for men to discuss their emotions and feelings . Considering class, one worker felt that situations linked to poverty (financial difficulties, health) didn't come out . There was also some question whether the tool would be as relevant for lower level or part-time care situations; concerns that it would be too in-depth for a part-time situation or a case where there are no problems. However, in three focus groups, where workers [who had assessed 75 caregivers] were asked specifically "Were there any cases for which the tool was not appropriate?" the response was always "No."

5.3.3. Integration of a new group of stakeholders into the health system

As discussed earlier in 5.3.1, the assessment tool made service providers much more aware of the situation and specific needs of caregivers. In this section, we will look at how the tool can potentially lead agencies to change their way of relating with caregivers, by seeing them as both partners and potential clients, rather than as resources or as peripheral to home care intervention. (This theme is also touched on in 5.3.1.5)

5.3.3.1. Legitimises caregivers' right to be heard

The first way the tool is relevant to agency practice is that it legitimises giving time to caregivers to hear their stories. This is relevant because it provides room for a new perspective (caregiver) within service provision and the larger context of policies related to families, and it legitimises caregivers to identify their own needs as distinct from those of the person they are caring for

What I think this tool affords us as care coordinators to do and be is hold a space for someone who has never had their space held before.

For most of the people I interviewed it was the first time that they ever talked this much at length. When it was my client, I found for myself that I had a better understanding of the entire family picture, even though I'd been working with these clients before. Just

because I focused only on the caregiving and the impact it was having on the caregiver, not on my client, made me perceive the client differently, perceive the whole situation and start working in a more family-oriented way in terms of services, and I feel I know them much better just through this.

Indeed of the 168 caregivers assessed, 60% reported that this was the first opportunity they had to discuss their situation and their comments suggest that it was meaningful experience for them. As one caregiver commented, “*It [the assessment] made me feel better to know that someone cares or is interested in my needs.*”.

5.3.3.2. Systematic & innovative: raises questions about the place of caregivers in home care programs

Second, the tool is relevant to policy and service because it is both systematic and innovative; the caregiver assessment tool covers material that current tools used in home care services do not. As such, it raises questions about the place of the caregiver in the home care practice and moves toward including the caregiver in the service plan. In addition to understanding caregivers as a client with needs, the tool is innovative in that it enables policy makers to understand caregivers in roles other than that of being yet another burden to the system. For example, over 80 percent indicate their interest in being a partner in ongoing decisions about their relative’s care and three quarters expressed interest in being involved in research on caregivers (72%). Despite the demand on their personal time and energy, about half of the caregivers expressed interest in various caregiver-focused activities. These include community groups, agency committees and groups consulted by government on policy-related matters. Further, in addition to being relevant to policy and service contexts, the research and implementation of the tool represented an important gain for caregivers because for the first time there is a tool that is addressed directly at them as both partner and client.

With current global assessment tool, there are no questions on how difficult tasks are for caregivers, so if the caregiver can do it, very often we tick off that it’s okay. “Yes she can do it, no problem, go to the next question.” The assessment tool does not let you miss anything, so it does not let you drop them (caregivers) through the cracks.”

5.3.3.3. Reinforces agencies’ caregiver orientation

Third, the tool assists to reinforce an agency’s caregiver orientation. For those sites where caregivers are not yet a priority, the research raised the awareness of caregiver needs, while for those where support to caregivers is already a priority, the research helped to re-orient agencies to re-focus on caregivers. One administrator in particular mentioned that although they have already adopted a caregiver focus, this is often forgotten in the action of service delivery.

5.3.3.4. Provides a rationale for directing services to caregivers & justifies intervention strategies

Fourth, the tool provides a rationale for current intervention with caregivers. In terms of relevance for practice, most workers discussed how the tool confirms their intervention strategies, settled their doubts and helped to justify service requests. That is, the material/responses given by caregivers gave workers the rationale for their demands for service. This was discussed particularly in relation to overwhelming need for respite. Going through the process of assessing and documenting caregiver issues helped workers to understand why the caregiver is burnt out, determine appropriate services and provide a rationale for intervention. The following quotes discusses the importance of this rationale for service provision.

If we have a tool like this, then we’re better able to lay out why they need this service or care or referral to that agency and it’s you know, a justification I guess.

It is thus clear that the assessment tool enabled workers to gather data which was previously missing from their evaluations by focusing on the other key actor in home care – the caregiver. The tool proved to be innovative with regard to existing assessment tools because it offered a specific time and space to focus on the caregiver and legitimised both workers and caregivers to do so. Even in cases where the care receiver and caregiver were well known to the assessor, the tool provided new information, insights and understanding. In this way the tool was

instrumental in identifying and documenting an emerging health issue – the well-being of caregivers and the factors which undermine it.

5.3.4. Were there any health impacts or caregiver well-being issues which emerged?

Because our project was not aimed at evaluating an intervention, but testing tools we can only address the question of whether any unanticipated health and well-being issues were noted during the project. Although the health and well-being of caregivers has been quite thoroughly studied by researchers, practitioners and administrators of home care agencies are less aware of the underlying factors which contribute to caregiver distress. As such, the tools opened workers' eyes to the extent and level of caregiver suffering.

At both Assessments A or B, less than 2/3 caregivers rate their emotional health as “good” or “excellent”, and at the same time, more than 2/3 report frequent (ie. sometimes, often, all the time) feelings in the past year of being unappreciated, helplessness, being overwhelmed, discouragement, anger, nervousness, anxiety, sadness, exhaustion and frustration. Similarly, less than 2/3 rated their physical health as good or excellent and at the same time about half report negative effects on sleeping and increased tiredness. As is often the case, respondents to this type of question have no realistic comparison to rate their health. The strengths of this tool are the questions about frequency of individual feelings and changes to elements of their physical health as these are recognised triggers of health issues. Because many caregivers frequently experience many of these triggers, it is reasonable to assert that caregivers' emotional well-being is in jeopardy and their physical well-being should be monitored.

A surprising 42% of the 168 caregivers interviewed indicated that they had recently experienced a stressful event in their lives, most frequently, the death or illness of a friend or family member and that this had had a negative impact on their emotional health causing feelings of sadness, frustration, depression, much anxiety and a considerable increase in their stress levels and feelings of insecurity. Too often evaluations of caregiver well-being fail to look outside of the caregiving situation to understand the diverse impacts on caregivers' lives.

5.3.5. Cost-effectiveness

This was not a pilot study for the implementation of the tool but rather a study to create and validate it. To that extent, all comments on cost-effectiveness are speculative.

Focus group participants, both practitioners and supervisor/administrators spoke about how adopting the tools would lead to improved services, improved practitioner efficiency, formalise current practices addressed to caregivers and open up new avenues for practice. This type of intervention, they felt, would be preventive in nature and would help anticipate caregiver burnout or family breakdown, thus decreasing emergency interventions. Intervening earlier, to ensure caregiver well-being, is also a strategy for preventing eventual abuse due to caregiver depression or exhaustion. As well, a thorough evaluation of the situation from both caregiver and care receiver perspectives would improve interventions by better targeting where to put resources and identifying exactly what resources and services are needed for a family to successfully continue caregiving. Thus, in the long run, it was felt that the use of the tools would save the system money.

5.3.6. What lessons were learned about implementing and testing the tools which might be useful to other regions/programs/settings? - Transferability

Given that many of the implementation strategies were identical for the two tools, we will treat them together in this section.

As indicated, the assessment tool was successfully implemented, for the time of the project, in eight different agencies involving over forty different practitioners. In all 168 valid assessment pairs were completed. The screening tool met with more difficulties in the implementation stage but we successfully completed 76 screens, a sufficient number to validate it.

Some of the implementation strategies which contributed to this successful outcome include bringing all the stakeholders on board in an active way; standardisation of procedures across the sites; attempting to take into

consideration the difficulties of agency-based research; and providing on-going consultation and support to practitioner-researchers and administrators.

5.3.6.1. Actively including stakeholders from conception to evaluation

Stakeholders, including caregivers, front-line practitioners and home care administrators, were involved in the project at all stages, giving credibility to the tools' eventual use in home care agencies. Not only is the research team composed of research and practice partners but stakeholders were interviewed at the outset to understand their conception of the tools, their content and their implementation; they were consulted on preliminary versions of the tools; they were interviewed at the end of the process to give their feedback on their experience with the tools. Various stakeholders' suggestions were invaluable in producing the tools and many of the questions included in them were taken directly from focus group discussions. Thus many stakeholders felt committed to the project.

5.3.6.2. Assuring standardisation

Standardisation at all levels of the project was an essential characteristic of the research and facilitated its implementation.

Building a common conception of the tools

From the start, it was very important that all team members have a common conception of the tools to be created and their use. Team members knew each other through their work but had never collaborated before on a research project. It was thus necessary at the first team meeting to openly and fully discuss our visions of the tools. To this effect, we produced a document for discussion on the premises underlying the need for screening and assessment tools for caregivers and the nature of these tools. This document advanced a number of statements which the team then debated, modified and adopted as a common framework for developing the tools. This framework led us to the conclusion that we would develop one tool to screen for risk situations and another which was aimed at going beyond identifying risk and difficulties but would attempt to help practitioners understand the conditions and the context in which caregiving takes place so as to appreciate the reality of all caregivers.

Bringing eight agencies on board

Parallel to the development of the tools we began negotiations with agencies in Nova Scotia and Quebec. As indicated in the methodology section, agencies were first provided with a common proposed agreement form and after discussions, a formal agreement (see Appendix E) was signed. All agencies signed the same agreement which provided another way of ensuring conformity across the different sites.

Training assessors and screeners with common training programs

Following the long process of developing the tools, presented in the methodology section, the next challenge with regard to standardisation arose when we moved into the field, beginning with the training of practitioners as to the use of the tools. Over fifty front-line workers in the eight agencies had to be trained in two languages. And to ensure standardisation of the testing of the tools, they had to be trained in similar if not identical ways by the eight different team members who assured the training. To that end, as explained in the methodology section, we wrote a training guide for team members which was a common instrument for explaining the project and the testing phase. They were also provided with an participant's kit to be given to each assessor or screener and containing information on the project (see section 4.2 for more detail).

As well, as indicted in section 4.2, much effort went into developing the user guides for the tools so that assessors and screeners have a common vocabulary for explaining the questions, if needed. Assessors and screeners were given explicit instructions in terms of posing each question as it was written and in the order they appeared in the tool, and this, even if they felt they already had the answer or that the question was irrelevant to the situation, explaining the importance of this rigor for research.

The tension between research and practice

When practitioners go out into the field, they are not in laboratory conditions and some of them had a tendency to adapt the assessment, and to a lesser extent the screening tool, to their traditional way of doing psycho-social evaluations or to the context of the interview. Despite these occasional departures from the rules of the research, it is astonishing that the vast majority of 50 workers were able to appropriate the tools for themselves and provide a valid research test of the tools.

Assuring standardisation in the translation

Of course, each document that was produced had to be translated. Although we had foreseen that the tools would be translated and had budgeted and taken this into account in our time framework, we had not foreseen the number of documents that would be produced to accompany the tools. Although the translation of the tools was verified by team members to ensure conformity with the originals, it should be pointed out that demands of translation are often minimised and perhaps even more time and energy would have been needed to ensure 100% reliability of the translation. Certain problems which were picked up during the testing phase will be corrected in the final version of the tools.

5.3.6.3. Integrating research with the everyday demands of practice

Introducing new tools aimed at caregivers into the daily practice of already overburdened home care assessors and service providers is a major challenge. Four main strategies were developed:

- compensating the agencies for the workers' time. We hoped that the honorarium offered be used to liberate staff but this was left to the discretion of each agency. Several administrators, indicated that this honorarium had been key in their ability to ensure participation of their agency. However, even with liberations, the majority of participating assessors were somewhat overwhelmed by the volume of work required to organise and do the assessments. To facilitate their work, the project assumed the costs of respite for participating caregivers, when necessary. However, this added work for the assessors who had to organise the respite.
- proposing that worker participation in the project be totally voluntary so as to overcome potential resistance in being involved in the project. In the focus groups we held with workers following the testing phase we learned that a minority of them felt that the research had been imposed on them. However, the majority were voluntary and even enthusiastic about being part of the project.
- offering a certain level of flexibility in the research protocol to take into account the realities of agency-based research. Because the research was implemented in real-life and not test conditions, we had to adapt to a number of unforeseen circumstances. Administrators in four of the eight participating agencies stated that the project had arrived at a bad moment or in a difficult organisational context due to restructuring, unanticipated increased service demands or a generally high level of fatigue on the part of the staff. This meant, for example, that some assessors and screeners were less available than foreseen, or that intake procedures were modified so that it was difficult to administer the screening tool. As well, the demands of the project were often in conflict with the demands of on-going practice and the majority of administrators mentioned how challenging it is to find a balance between research and practice demands. To that extent, we must emphasise the dedication and excellent work of the practitioners who saw the project through
- getting practitioners to buy into the research by choosing agencies which were already open to caregiver issues.

Finally, despite their generally "pro-caregiver" position, many home care assessors have become used to working with standardised questionnaires and measures with little room for interpretation. They are also generally overwhelmed with the volume of forms and statistics they must complete and have a general aversion to "more paper work". However, despite some initial negative reactions to a lengthy tool and to the strictness of the research protocol, in most cases, the tool sold itself because of the positive impacts described in sections 5.3.1-5.3.4. About one quarter of the assessors explicitly mentioned in their written comments that they found the tool increasingly

appropriate and that it took less time to complete, as they became more familiar with it. *“The more I use it, the more I appreciate how it reveals caregivers’ situations and needs.”*

5.3.6.4. Ethical questions

A third area of issues arose around a number of ethical questions which were raised throughout the development and implementation stages.

Raising issues and offering nothing

One of the major ethical questions that had plagued us from the conception of the project was the fact that we would be putting caregivers through two lengthy interviews during which we provoked discussions on various potentially difficult and problematic areas of their lives, during which we even ask them to name those services and resources which would be helpful to them, all the while explaining to them that this is just a simulation and that it will have no impact on the level or type of services they or the care receiver are currently receiving.

Our formal agreement with the agencies stipulated that workers were not to modify services based on the information gathered through the research process. This was also indicated in the consent forms signed by each practitioner and each caregiver (see Appendix F).

Some of the Quebec CLSCs were not comfortable with this clause since their workers do not only assess the care situation but also provide the services to the care recipient, and sometimes the caregiver, and thus have on-going relations with both. We thus wrote into the agreements with the CLSCs an special clause indicating that assessors could ask for specific permission from the caregiver to have information obtained during the assessment consigned to an establishment file and/or complete their own assessment outside the research process and a specific consent form was written (see Appendix F). Several workers, in Quebec, prevailed of this release and services were increased in many instances once workers realised the extent of the impacts of caregiving on the caregiver. In Nova Scotia some interviews were stopped because the assessor realised that the situation was critical and an immediate intervention was necessary.

However some other workers expressed frustration and guilt that there were no services to meet the identified needs of caregivers and discussed the difficulty of not being able to respond.

Identifying needs and not doing anything about it is a gross injustice.

Do you want to do this if you’re just opening up a can of worms...

If I’m just there to frustrate you and you can’t have what you need... I’m not comfortable asking all these questions and leaving them hanging.

The team did provide assessors with a pamphlet for each caregiver listing existing resources and services and adapted to each site (see Appendix G).

Ethics of knowing

Workers discussed the dilemma of knowing. Workers felt guilty and frustrated that they were aware of unmet needs but not able to intervene because there are so few services and resources available for caregivers. In fact one site refused to use the tool in the future if resources and services were not available. For many, the discussion may be described as the ‘ethics of knowing’. After participation in this project the workers know that there is a need for caregiver services, however, they do not have any services to offer.

(...) I was frustrated not being able to intervene once I had identified needs, because I became aware that certain people had [...], important needs, for one of them at least. I was really left hanging. I found that people were suffering terribly! It was terrible for me... it really left an impression.

5.3.7. In summary: Lessons for Successful Implementation

Lessons which we learned for successful implementation of agency-based research leading to successful outcomes are :

1. the necessity of frequent interaction between team members to ensure a common understanding of all the aspects of the project;
2. the importance that agency-based research be properly implemented including a clear presentation of the roles and responsibilities of the research team, the agency and the workers; stipends to free staff and the assurance that staff participation is voluntary;
3. the importance of ensuring the conditions necessary to facilitate caregiver participation such as providing respite;
4. the importance of learning the culture of the agency and its workers before attempting to introduce the research and adapting the protocol in line with this culture;
5. the importance of offering on-going, regular and accessible support and supervision to practitioner-researchers;
6. the importance of ensuring on-going contact with agency administrators;
7. the importance of developing user-friendly material which acts as a support to practitioner-researchers;
8. the importance of helping workers work through the ethical dilemmas posed by the research.

5.3.8. Challenges for the transferability and future implementation of the tools

The screening tool proved to be highly valid and relatively simple and quick to use. We could see it as potentially interesting not only home care agencies across Canada, but also for use in physicians' offices and out-patient departments. It will have to be tested to ensure its validity for caregivers of other than elderly persons. As for the assessment tool, as indicated in sections 5.2 and 5.3.1.4, it has good potential for use in home care agencies across the country, as it is valid and reliable for caregivers to the disabled elderly living in urban or rural communities, and appear to work well to identify the needs of caregivers in other situations including caring for adults with physical and mental disabilities, mental health problems or chronic diseases, or being of minority ethno-cultural (sample size of these groups prevented us from doing statistical validation). However, a certain number of challenges stand in the way of their implementation.

Pre-requisites to implementation

1. Caregiver status must be clarified

Before caregiver screening and assessment tools can be implemented into an agency, it is essential that caregivers be given a status in home care policy and within the service package. Because of insufficient resources, lack of time and inappropriate tools, there is a culture of normalcy regarding the situation of caregivers. To that extent, it will become necessary to identify caregivers as both potential clients of home care services and as potential partners in supporting an incapacitated person in the community. Both of these statuses will require the addition of specific services and resources, but will also require a shift in agency thinking and practice.

2. Caregivers must be an agency priority

Given the implications of implementing screening and assessment tools, in particular in terms of the financial and human resources involved, it is clear that the shift to conceptualising caregivers as potential clients and/or partners of home care services must be an agency priority at all levels. In particular, administrators and supervisors must be in full agreement to give front-line workers the support they will require. As well, a number of administrative

considerations will have to be addressed in terms of whether caregivers will become clients with their own files and the impact this may have on current organisational and budgetary practices. Screening for high risk caregiver situations has implications for the organisation of in-take services and the introduction of caregiver assessments will undoubtedly also lead to the necessity of reorganising service delivery.

3. A common conception of the tools

Once caregivers are designated as an agency priority and their status has been clarified, it is important that all agency personnel arrive at a common understanding of the purpose and the use of the tools. In particular, several conceptions of the potential use of the assessment tool were voiced by assessors and administrators including a statutory tool to be administered to all caregivers identified by the agency; a tool to be used as needed based on worker discretion ; a tool for crisis situations. As well, agency staff differed in opinion as to the optimum timing for administering the tool. Should it be done at intake, at the same time as the incapacitated person is evaluated or once services are in place based on the latter's evaluation? As well, who should assess and give services to caregivers?

4. Revisions to the tools and their integration with existing tools

Given current assessment practices in home care agencies, the introduction of new tools and in particular a lengthy psycho-social assessment tool presents major challenges at several levels. Many agencies are used to doing functional assessments to determine care recipient needs, with a secondary place given to the psycho-social aspects of the situation. Once agencies have determined that addressing caregivers' situations is a priority, they will have to be convinced that a psycho-social assessment is the most appropriate one. Front-line assessors are also leery of "more paperwork" given the multiplication of forms and assessments to be completed. This situation will be in part rectified by the fact that many provinces are developing a single home care/long-term care assessment tool with modules for specific situations and a caregiver assessment tool could be a specific module. This will also address the problems raised by many stakeholders concerning the integration of the assessment tool with existing tools. The length of the tool was also raised as an obstacle by many workers and administrators. However, if the caregiver assessment is seen as an ongoing evaluation over a period of 2-3 visits and given that in a non-research use of the tool assessors will adapt the different sections of the tool to the reality of the situation being evaluated (during the research phase assessors were obliged to ask all questions in the order they were written and could eliminate nothing no matter what the situation), it's length should not pose the same problems raised during the research stage. As well, comments concerning the awkward wording of some questions or the redundancy of some questions have been addressed in the recommendations for modifying the tool to be found in Appendix K. Concerning the screen tool, length was not seen as a problem, but integration with existing screening tools (for abuse, falls, conjugal violence, etc.) was suggested.

5. Staff must be on-board

Given potential worker resistance to added responsibilities and in particular additional screening and assessment tools to administer, in-take workers, assessors, and front-line practitioners must be consulted and included in all implementation decisions from the outset.

6. Training must be assured

Practitioners will have to be trained in line with the new orientations developed by the agency resulting from the new conception of caregivers and their relation to home care services. Practitioners will need to modify their practice or elements of their practice and thus will require training on caregivers' situations and issues and practice skills for meeting the needs of caregivers. As well, they will have to be trained in the use of the tools and given on-going supervision to ensure standardisation of the interpretation of the scoring codes.

7. Increased resources for caregivers and increased human resources

Perhaps the most delicate issue with regard to the future implementation of the tools is that they will, in the short-run at least, require a financial investment from government, both in terms of the additional human resources needed to

support this new group of potential clients and in terms of developing the services and resources which caregivers need in order to maintain their responsibilities without undue negative effects to their own well-being.

However, it appears critical that, as a society, we recognise the immense contribution of caregivers and take a position on the issue of according public support to caregivers so that appropriate resources be allocated. Social norms and standards need to exist which outline what is socially acceptable in terms of our expectations of caregivers so as to guide policy, intervention and service allocation.

5.3.9. Unanticipated outcomes

There were several unanticipated positive outcomes of the project. First, we were surprised to what extent participating practitioners and supervisors felt their participation was perceived as a form of training. Many spoke of how they had been privileged to be part of the project because they are now better trained on caregiver issues. Second, we had not foreseen the impact the assessment tool would have on current practice given the research nature of the project and the stipulation that information gathered during this process should not impact on service delivery. However, as mentioned in sections 5.3.1.6 and 5.3.2.1, the testing of the assessment tool enabled a majority of participating practitioners to identify problematic situations which required immediate intervention but which otherwise might have gone unrecognised. Finally, we were unprepared for the overwhelming interest shown by the majority of agencies and researchers contacted during Phase I and which continued throughout the life of the project.

5.3.10. Implications for program/service development

At this time, there exist only token policy and program efforts at both the national and provincial levels including taxation policies and volunteer support, with little emphasis on the role of public services with regard to caregivers. This clearly indicates the need for the development of programs and services addressing caregiver needs. By identifying the underlying causes of caregiver burden and distress, the tools created by this project can provide the information necessary to develop specific programs and services which will ensure caregiver well-being. Their well-being must be of equal priority in the health-care system as the well-being of the disabled persons they care for. The contribution of the tools is that they enable practitioners and program developers to have a comprehensive understanding of caregivers' situations.

5.3.11. Potential policy implications

Our findings raise questions about the fact that there has been a considerable transfer in the location of care, from hospital to home, and yet home care services (excluding nursing and some rehabilitation care) are not recognised as medically necessary and thus not universally accessible and free. This problem also exists with regard to the costs of medication, equipment and home adaptations. Caregivers are thus being forced to pick up the slack, provide the services and assume the costs which were, until recently, provided by the public sector. Further, this study raises questions with regard to the on-going assumptions in current policy concerning the role of caregivers. Based on our findings, we would question the idea that we can continue to automatically assume caregiver involvement at the level that policy does today without seriously compromising those people's well-being. Caregivers must be specifically named in health-care and home care policies and they must be targeted as having specific needs for ensuring their well-being.

6. Dissemination Plan

6.1. Primary and secondary target audiences

Our primary audience is composed of policy-makers, administrators and practitioners in home care and more widely in front-line care. Our secondary audience includes caregivers, academics, training institutions and the general public.

Our preliminary contacts with agencies from around the world in Phase I generated strong interest in the project from both public and private spheres. Many agencies commented that they had been considering implementing such a tool for caregivers but could neither find a satisfactory source nor the time and resources to develop one. From the key

contacts and front-line agencies who responded from within North America and abroad, eighty-three (40%) requested a copy of the final Executive Summary and information on how to review the tools developed through the project⁷.

6.2. Methods to be used to reach them and time lines

- meetings with representatives from the provincial Ministries of Health - On-going

Negotiations have begun with the Quebec Ministry of Health concerning the eventual integration of our tools into the new comprehensive home care assessment tool being tested at this time. Prince Edward Island and Nova Scotia have also shown some interest in the tools, as has Veteran's Affairs.

- press release to inform the media and the public of the results of the study - March 30, 2001
- developing an accessible lay-person's document for front-line practitioners, caregivers and the general public - June 2001
- mass mailing of the executive summary with indications concerning how to access the full report, the lay-person's document and the tools - June 2001
- using existing institutional websites to disseminate the full report - June 2001
- dissemination of the tools on request - As of March 15
- presentations to participating agencies - May- Dec. 2001
- presentations to other groups in the community - As of May 2001
- scientific conferences - Particularly in 2001-2002
- scientific articles - 2001-2002

Specific journals for articles and specific events for presentations

We plan to submit articles to the following journals: The Gerontologist, The Canadian Journal of Aging, Qualitative Health Research as well as journals in the fields of nursing and rehabilitation and possibly other journals in the field of aging.

We have already presented this research (Phases I and II) at meetings of the Canadian Association of Gerontology; the Canadian Home care Association; the Alzheimer's Society of Nova Scotia; the Department of Family Studies and Gerontology, Mount Saint Vincent University; the Advisory Committee on Health Services; the Central and Regional Health Board Forum, Nova Scotia; and the J. W. McConnell Family Foundation⁸

Future presentations include: the Care-Management Conference of the American Association of Aging; the International Association of Gerontology; the Alzheimer Society of Canada, the Canadian Association of Schools of Social Work

Planned releases to media

A press release was distributed in Halifax in the winter of 1999 to announce the project. There was no press coverage to our knowledge. During the course of the project media coverage included: an interview on *This Morning*, CBC

⁷ Contact information for these individuals and organisations has been compiled to use at time of dissemination.

⁸ For detailed list of presentations see Appendix L.

radio and an article in *Vital Aging*, Vol. 6 (2), Bulletin of the CLSC René-Cassin/Institute of Social Gerontology. We will provide a press release to media announcing the tools at the end of the embargo period.

References

- Altman, D.G. (1991) *Practical Statistics for Medical Research*. Chapman & Hall, London.
- Brody, E. M. (1990). *Women in the middle : Their parent-care years*. New York: Springer Pub. Co.
- Cantor, M.H. (1983). Strain among caregivers: A study of experience in the United States. *The Gerontologist*, 23, 597-604.
- Cranswick, K. (1997). Canada's caregivers. *Canadian Social Trends*, 47, 2-6.
- Guberman, N., Maheu, P. & Maillé, C. (1993). *Travail et soins aux proches dépendants*. Montréal: Les Éditions du Remue-ménage.
- Guberman, N. et Maheu, P. (2000). Le rapport entre l'adéquation des services de maintien à domicile et l'insertion au travail des personnes soignantes , *Revue canadienne du vieillissement* 19(3)
- Guberman, N. & Maheu, P. (2002). Conceptions of Family caregivers : implications for professional practice, *Canadian Journal of Aging*, 21(1) (accepted for publication)
- Hooyman, N. (1990). Women as Caregivers of the Elderly: Implications for Social Welfare Policy and Practice. In D. Biegel & A. Blum (Eds.), *Aging and Caregiving: Theory, Research, and Policy*. Newbury Park: Sage Publications.
- Keating, N., Fast, J., Philips, J., & Cranswick, K. (1999). *Eldercare in Canada: Content and Consequences*. Ottawa: Ministry of Industry
- Keefe, J. & Fancey, P. (1997). Financial compensation or home care services: Examining differences among program recipients. *Canadian Journal of Aging*, 9(3), 3-25.
- Keefe, J. & Fancey, P. (1998). *Financial compensation versus community supports: An analysis of the effects on caregivers and care receivers*. Report submitted to Health Canada. Halifax..
- Keefe, J. M. & Medjuck S. (1997). The contribution of long term economic costs to predicting strain among employed women caregivers. *Journal of Women & Aging*, 9 (3), 3-25. Lang & Brody, 1983
- Lavoie, J.-P. et al. (1998). *Les modèles de relations entre les services formels et les aidantes naturelles. Une analyse des politiques de soutien à domicile du Québec*. Montréal: Direction de la santé publique.
- Lesemann, F. & Chaume, C. (1989). *Familles-Providemce, La part de l'État*. Montreal: Editions Saint-Martin.
- Maddock, Kilner & Isan (1998) *Carer Needs Assessment Trial*. Unley, SA: Carers Association of South Australia
- McKinnon, A. & Odynak, D. (1991). *Elder Care, employees and employers: Some Canadian evidence. A discussion paper prepared for the demographic review secretariat*" *Health and Welfare Canada*. Population Research Laboratory, The University of Alberta, 44p.
- Neal, M. B., Chapman, N.J., Ingersoll-Dayton, B. & Emlen, A. C. (1993). *Balancing work and caregiving for children, adults, and elders*. Newbury Park,CA:Sage.
- Paquet, M. (1999). *Les professionnels et les familles dans le soutien aux personens âgées dépendantes*. Paris, Montreal: L'Harmattan.

Scharlach, A. E., Sobel, E. L. & Roberts, R.E.L. (1991). Employment and caregiver strain: An integrative model. *The Gerontologist*, 31 (6), 778-787.

VON Canada, (1998) *Caregiver Symposium: Reports and Recommendations*. Document miméo.

Ward-Griffin, C. & McKeever, P.(2000), Relationships between Nurses and Family Caregivers: Partners in Care?, *Advances in Nursing Science*, 22(3): 89-103