

**Development of screening and assessment tools  
for family caregivers**

**NA 145**

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## **Executive summary**

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.

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 the tools' development. The initial development of the tools was informed by three methods: 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; 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 the 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 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 at the 7 sites to new caregivers requesting services immediately after they had completed their intake interview and had obtained consent. Follow-up interviews were administered by the researchers using the Caregiver Burden Screen (Rankin et al.). In all, 87 caregivers participated, but 11 of the completed tools 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. The screening tool was validated for its internal and external consistency using Alpha Cronbach measures.

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.

## **Results**

### **The screening tool**

The project developed a screening and an assessment tool. 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.

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 it 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. And the test for internal consistency indicates that the scoring of assessment areas informs related key areas of concern.

Based on analysis 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. 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. 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; that training be assured.

However, a major challenge stands in the way of future implementation: the fact that caregivers presently have no 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.

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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.

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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.

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