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Making a Difference: Exploring the Experiences and Needs of Caregivers

Summary Report

**Prepared by Hospice Toronto and First Unitarian Congregation of
Toronto**

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Abstract

New Horizons Caregiving Project

“Making a Difference:

Exploring the Experiences and Needs of Caregivers”

Purpose: To partner with other diverse community organizations, to engage seniors who have been caregivers for the purpose of developing a caregiver support model that is based upon actual expressed (rather than perceived) caregiver needs. **Objective:** To engage a diverse group of seniors and other community members who have been caregivers themselves to collect information about their experience, perceptions and concerns as a caregiver (for either a family member or friend with a life threatening illness); to develop a caregiver support model based on the collected information focusing on the most valued supports as well as expressed gaps; pilot and evaluate a support model; implement an outreach process through training seminars, written and electronic materials so that formal and informal organizations, community groups and individuals will have access to these caregiver support models. **Method:** For diversity, community and partnership purposes, the sample population was comprised of previous caregivers, particularly those over 55, including a Portuguese Women’s group, faith based congregants, caregivers from the Disability and Asian community and Hospice volunteers who had personal and informal caregiver experience. The design evolved into a mixed method approach (focus groups, a resource summary survey, and an online application of the focus group and resource survey questions). There were 91 participants who were recruited through snowball sampling, word-of-mouth and information/promotion initiatives. **Outcomes:** The development and facilitation of an enhanced Expressive Arts group format and a Hospice Caregiver Resource Package that integrated the expressed needs of the majority of participants, those supports they would have like to have had but did not receive. Results demonstrated consistent themes: that access to a caregiver support group, being listened to, and strategies for self care, disease and system specific education and assistance with navigation of the healthcare system were needed. Findings were based on narrative not empirical data.



The Heart is Many Things

The centre of caregiving is the heart.
With textures both rough & smooth,
in constant movement, giving and receiving
a pendulum rhythm through days & seasons.

Concern & joy
Illness & fear
Despair & back again to serenity.
Spirit & breath.
Whimsy & freedom.
The elementals of Being.

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(Written by participants during the Expressive Arts Session)

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INTRODUCTION

This project began from the work of Hospice Toronto and its experience in providing in-home supports to people with a palliative condition or illness through the provision of trained volunteers and the professional case management of staff. Hospice Toronto recognized that caregivers are critical to the care of the organization's clients, that many primary caregivers are seniors - defined as 55 years and older for this project and that additional research was needed to better understand caregivers' support needs.

Likewise, First Unitarian Congregation of Toronto, an organization that has existed as a religious community since 1845, shares the experience of many faith communities in the practice of supporting congregation members who are suffering from a serious condition or illness through caring committees that keep track of and send volunteers out to ill members.

In a fiscal environment where publicly-funded services are unable to keep up with the demands of an aging population, the need to understand cost-effective supports and interventions is paramount. It was with this in mind, that Hospice Toronto approached First Unitarian Congregation of Toronto to partner in the funding application to New Horizons. In the spring of 2009, the two partner organizations undertook to look into the experiences and needs of caregivers so that they could better understand their support needs and could embark on a pilot project that would test out a new model of caregiver support.

The goal was to "make a difference," to be able to learn from caregivers' personal experiences and to share information that would help many other health, social service, community and faith organizations to make a difference as well, by improving supports to stressed and over-burdened caregivers.

In essence however, the heart of this study was based on the premise that often individuals have little or no choice in their taking on the role of being the "caregiver." Therefore, it was our intent to learn rather than assume what those needs may be.

It is important to note that while we have captured the data and anecdotal input, for clarity, this report (and the project), were not intended as an empirical research based study but as a starting point (at this point in time) for capturing data and formulating information, to be used to inform others and planning for future caregiver support initiatives.

BACKGROUND

According to the Canadian government's paper *Informal Caregivers in Canada: A Snapshot*, in 1996, "2.85 million Canadians provided care to at least one person with a chronic problem or disability." A recent Globe and Mail article (*Costs to soar as aging Canadians face rising tide of dementia*, Picard, A, 2010) noted that there is a "tremendous burden on the health and social services systems and, above all, families providing care to their loved ones."

But is caregiving only a burden for caregivers? According to Lawton et al (1991), caregiving results in both costs and rewards to those who provide care. If caregiving is a "well-intentioned action that is given willingly to a person with whom there is a personal relationship and that produces an immediate or delayed positive response to the recipient" (Hupcey, 1998), then this study is a well-intentioned action to support caregivers to reduce their burden and enhance the positive aspects of their experience.

PURPOSES

The specific objectives of the project were to: i) engage seniors and other community members who have been caregivers themselves to collect information in focus groups about their experience, perceptions and concerns as a past caregiver, ii) develop a caregiver support model based on collected information, iii) pilot and evaluate the support model, and iv) implement an outreach process describing caregiver support models.

METHODOLOGY

The project's Advisory Committee determined that a focus group approach was ideal for engaging caregivers, giving them a place of safety and connection with others, and capturing the rich language of experience. The goal was to get beyond the statistics and encourage a range of anecdotes and interactions that would shed light on what it was like to be a caregiver. Paper surveys were also constructed to gather person-based responses to demographics, support needs and evaluation questions; since we were unable to accommodate all those with scheduling problems, it was decided to give people who could not attend a focus group the option of answering an online survey.

The primary target group for the project was former caregivers, "caring for a loved one with a life-limiting condition," over 55 years of age, who were known to the two partnering organizations conducting the research. Current caregivers and any caregiver under 55 years of age, who wished to participate, were also included.

The project staff also approached a Portuguese senior's organization a widowed parents group and formal and informal caregivers from a Disability organization and members of the Asian community.

FINDINGS

Sixty-three people attended four focus groups while another 27 completed the online version for a total of 90. Fifty-nine (66%) of the participants were 55 years of age or older and 74 (82%) were women. An equal number of participants (45) reported that they were former or current caregivers and 49 (55%) indicated that they were caregivers for four years or more. Cancer (33) and dementia (23) led the way in reported diagnoses. Daughter (19), Volunteer (12), Staff (12) and Husband (10) were the most commonly reported relationships to the person cared for.

The focus groups themselves turned out to be much more than research vehicles, as a large number of participants referred to the "power of connecting with others," as a "touching experience" and of knowing "we are not alone," in the evaluation survey.

Table 11: Comparison of the Ranking of the Four Focus Groups and Online Surveys in Response to the Question: Which of the following supports would you have liked to have had but did not?

Faith Community	Disability Organization	TOTAL
<ul style="list-style-type: none"> 1. One-on-one supports 2. Group supports 2. Internet-based information on caregiving 2. Internet support 3. Bereavement follow-up 4. Information on agencies that provide community support 4. Practical support 4. Complementary therapies 5. Financial assistance 5. Help with pets 	<ul style="list-style-type: none"> 1. Bereavement follow up 2. One-on-one supports 3. Assistance with forms or paperwork 3. Practical education on how to care for loved ones 3. Internet support 3. Help with pets 4. Information on agencies that provide community support 4. Financial assistance 4. Group supports 4. Practical support 4. Complementary therapies 4. Internet-based information on caregiving 5. Legacy work 	<ul style="list-style-type: none"> 1. Group supports 1. Practical education on how to care for loved ones 2. Information on agencies that provide community support 3. One-on-one supports 4. Bereavement follow-up 5. Practical support <p>Miscellaneous *</p> <ul style="list-style-type: none"> 1. Group supports 1. One-on-one supports 1. Practical support 2. Information on agencies that provide community support 3. Financial assistance 3. Complementary therapies 3. Practical education on how to care for loved ones 3. Internet support
Hospice Organization	Portuguese Women	Online Surveys
<ul style="list-style-type: none"> 1. Information on agencies that provide community support 1. Group supports 2. Bereavement follow-up 3. One-on-one supports 3. Hospice in-home volunteers 3. Complementary therapies 3. Legacy work 3. Practical education on how to care for loved ones 4. Practical support 4. Assistance with children's issues 4. Internet-based information on caregiving 5. Internet support 5. Care with pets 	<ul style="list-style-type: none"> 1. Financial assistance 1. Practical education on how to care for loved ones 2. Information on agencies that provide community support 3. Group supports 3. Practical support 3. Complementary therapies 	<ul style="list-style-type: none"> 1. Group supports: caregiver 2. Information on agencies that provide community support 2. One-on-One supports 2. One-on-One supports: on the phone 3. Practical support: respite providers 3. Practical education on how to care for loved ones 4. One-on-one supports: in person 4. Practical support: grocery shopping 4. Internet-based information on care giving 4. Bereavement follow-up: grief counselling

Table 12: Unique Features of the Four Focus Groups

Faith Community	Disability Organization
<ul style="list-style-type: none"> • Used faith community to support through care team involvements • Use of and need for pastoral care and counselling commonly cited • Strong awareness of psycho-social dimensions • Several mentions about use of private nursing, paid caregivers • Strong sense of accomplishment, personal and spiritual growth • Reliance on community supports highly valued. • Expectation that services s/b more effective, sensitive 	<ul style="list-style-type: none"> • Mostly consisted of formal caregivers working in residential and institutional settings • Wide variety of clients' ages, diagnoses, number of caregiving experiences • More reliance on, and problems with, health and social service organizations and workers • Advocacy most commonly referenced • Significant knowledge of service 'system' and its shortcomings • Clients' appreciation important, knowing they made a difference
Hospice Organization	Portuguese Women
<ul style="list-style-type: none"> • Many were trained volunteers providing in home caregiving (not always clear if they were speaking from their personal or volunteer caregiving experiences, or from their observations of caregivers they were supporting as volunteers) • Seemed plugged into the 'system', even to the extent of making constructive criticisms of that 'system', knowing what they were missing, not getting enough of • Had a greater appreciation of bereavement services 	<ul style="list-style-type: none"> • Financial problems cited often due to loss of income • Cultural conflicts (not fully explained) • Language barriers and translation needs • Expectations that females do most of the caregiving

The above table provides a summary comparison of the distinctive features of the four focus group participants. It does not repeat those themes (such as group supports, need for information and practical help, etc.) that were commonly expressed by all groups.

Summary Survey

The tables below contain the results of the Summary Survey which was handed out at for completion at the focus groups and an identical survey was completed by the online participants.

Tables 9a, b and c answer the following question:

Which of the following supports would you have liked to have had, but did not?

Table 9a: Responses ranked by summary survey responses (focus group)

Answer Options	Summary Survey # (%)
Practical education on how to care for loved ones	23 (45.0)
Group supports	23 (45)
Information on agencies that provide community support	22 (43.1)
One-on-one supports	21 (41.1)
Bereavement follow-up	20 (39.2)
Practical support	18 (35.2)
Complementary therapies	17 (33.3)
Group supports: caregiver	16 (31.3)
Financial assistance etc.	16 (31.3)
Internet support	15 (29.4)
Internet-based information on caregiving	13 (25.4)
Grief counselling	11 (21.5)
Legacy work	11 (21.5)
Respite providers	10 (19.6)
One-on-one supports in person	9 (17.6)
Massage	9 (17.6)
One-on-one supports on phone	8 (15.6)
Hospice in-home volunteers	8 (15.6)
Homemaking	8 (15.6)
Internet support: Online support groups	8 (15.6)
Help with pets	8 (15.6)
Reiki	8 (15.6)
Assistance with forms/paper work	7 (13.7)
Internet support: websites	7 (13.7)
Meal support	6 (11.7)
Assistance with children's issues	6 (11.7)
One-on-one	6 (11.7)
Group	6 (11.7)
Grocery shopping	5 (9.8)
Home maintenance	5 (9.8)
Group supports expressive arts	5 (9.8)
Outdoor maintenance	5 (9.8)
Therapeutic touch	5 (9.8)
Transportation	4 (7.8)
Reflexology	3 (5.8)
Respite care	0 (0.0)
Comments	4 (7.8)
Answered question	51 (100%)
Total number of choices made/ per person	369 / 7.2

Table 9b: Responses ranked by online survey participants

Answer Options	Online Survey # (%)
Group supports: caregiver	11 (40.7)
Information on agencies that provide community support	9 (33.3)
One-on-one supports	9 (33.3)
One-on-one supports on phone	9 (33.3)
Practical education on how to care for loved ones	8 (29.6)
Respite providers	8 (29.6)
Internet-based information on caregiving	7 (25.9)
Grief counselling	7 (25.9)
One-on-one supports in person	7 (25.9)
Grocery shopping	7 (25.9)
Bereavement follow-up	5 (18.5)
Complementary therapies	5 (18.5)
Massage	5 (18.5)
Homemaking	5 (18.5)
Internet support: Online support groups	5 (18.5)
Internet support	4 (14.8)
Assistance with forms/paper work	4 (14.8)
Hospice in-home volunteers	3 (11.1)
Internet support: websites	3 (11.1)
Meal support	3 (11.1)
One-on-one	3 (11.1)
Home maintenance	3 (11.1)
Financial assistance etc.	2 (7.4)
Help with pets	2 (7.4)
Assistance with children's issues	2 (7.4)
Group	2 (7.4)
Group supports expressive arts	2 (7.4)
Transportation	2 (7.4)
Reflexology	2 (7.4)
Legacy work	1 (3.7)
Reiki	1 (3.7)
Outdoor maintenance	1 (3.7)
Group supports	N/A
Practical support	0 (0)
Therapeutic touch	0 (0)
Respite care	N/A
Comments	2 (7.4)
Answered question	27 (100%)
Total number of choices made/per person	149 / 5.5

Table 9c: Ranked by total focus group and online survey responses

Answer Options	Total Survey # and (%)
Information on agencies that provide community support	31 (40)
Practical education on how to care for loved ones	31 (39.7)
Group supports: caregiver	27 (34.6)
One-on-one supports	30 (34.5)
Bereavement follow-up	25 (32)
Group supports	23 (29.5)
Complementary therapies	22 (28.2)
Internet-based information on caregiving	20 (25.6)
Internet support	19 (24.3)
Financial assistance etc.	18 (23)
Practical support	18 (23)
Respite providers	18 (23)
Grief counselling	18 (23)
One-on-one supports on phone	17 (21.7)
One-on-one supports in person	16 (20.5)
Massage	14 (17.9)
Homemaking	13 (16.6)
Internet support: Online support groups	13 (16.6)
Grocery shopping	12 (15.3)
Legacy work	12 (15.3)
Assistance with forms/paper work	11 (14)
Hospice in-home volunteers	11 (14)
Internet support: websites	10 (12.8)
Help with pets	10 (12.8)
Meal support	9 (11.5)
Reiki	9 (11.5)
One-on-one	9 (11.5)
Home maintenance	8 (10.2)
Assistance with children's issues	8 (10.2)
Group	8 (10.2)
Group supports expressive arts	7 (8.9)
Transportation	6 (7.6)
Outdoor maintenance	6 (7.6)
Therapeutic touch	5 (6.4)
Reflexology	5 (6.4)
Respite care	0
Comments	6 (7.6)
Answered question	78 (100%)
Total number of choices made/per person	518 / 6.6

Limitations

In descriptive studies such as this one, the primary goal is the collection of experiential data. The data suggests priorities within the context of powerful statements and personal observations of those who have been or are on the front lines, caring for loved ones.

- It is important to note that while we have captured the data and anecdotal input, for clarity, this report (and the project), were not intended as an empirical research based study but was a starting point (at this point in time) for capturing data and formulating information
- While there is no obvious reason to question the validity of the results, they cannot be generalized to the larger population of caregivers because of the small number of respondents and the non-random sampling techniques employed
- The use of multiple survey instruments complicated tabulation of results and was more challenging in terms of analysing and comparing results among sub-groups
- The relationship question in the demographic survey was misunderstood by more than half of the respondents. For example, some women reported they were the “wife” of their loved one while other women responded with “husband”
- Some demographic questions did not allow for multiple responses although a significant minority of respondents in the paper survey (those attending focus groups) said they were both ‘current’ and ‘past’ caregivers and therefore had multiple responses to the ‘years’, ‘diagnosis’ and ‘relationship’ questions
- The answers to questions such as that pertaining to the diagnosis of the caregivers’ loved one and length of time they were a caregiver would have been easier to tabulate if asked as a forced choice (e.g. Cancer, Heart Disease, etc.) and as grouped data (Under 6 Months, 6 Months to 1 Year, etc.) respectively
- Demographic, summary survey and focus group evaluation surveys were completed separately preventing the possibility of cross tabulation and analysis of data (e.g. to investigate whether there was a difference between male and female caregivers’ expressed support needs)
- The online survey did not ask respondents which caregiver group they were affiliated with, removing the possibility of comparing or aligning online group-by-group results to those from the different focus groups

- The data collection instruments did not ask participants to distinguish between their personal and primary (informal) caregiving experiences and their experiences as secondary (e.g. long distance) or formal (paid) caregivers or as trained volunteers. As a result, it was difficult to separate and understand responses within the different caregiving contexts
- The consideration/recognition that past vs. current caregiver roles will impact need, perception, interpretation and potentially the interest in or responses to the pilot
- Time to test a pilot based on the highest levels of expressed need may not have been available; results will be addressed on an ongoing basis moving forward

RESULTS AND RECOMMENDATIONS

The following recommendations are crafted from the extensive amount of information provided by the caregivers who participated in the different stages and formats of this project. They have spoken and have been heard.

These recommendations attempt to provide potential solutions to each of the common themes that were described in this study with the conviction that none should be overlooked to ensure system-wide high level standards of care and delivery.

Themes From the Accumulated Findings	Recommendations
Ongoing Caregiver Group Supports are needed, such as expressive arts, other group supports and self-care workshops	Relevant health organizations should run workshops held for and by hospice and faith communities' caregivers associated with their clients' and members
One-On-One Counselling was a great need expressed by many caregivers	Contact information for counselling resources must be maintained
Family Counselling is also much-needed, and in culturally sensitive modalities, in order to help caregivers struggling with the raw emotions and open conflicts that beset many families	Contact information for counselling resources must be maintained
Practical Supports such as housekeeping, driving to appointments, picking up groceries, etc. are needed to	Often these supports are available but unknown. Better case management from

alleviate caregiver burnout	existing health organizations is needed to inform caregivers
Information About the System and Sources of Information is essential to address the very significant message from caregivers, that they are badly uninformed	<p>Inter-agency initiatives must be undertaken to ensure that their first contact with any one organization will ensure them access to needed information</p> <p>New Media Strategies using the Internet and social networking must be explored to provide support and information and education to caregivers</p> <p>The Dissemination of Reports produced for focus group and pilot project participants through print and online media is an important task for Hospice Toronto and First Unitarian to undertake in order to reach the hands of caregivers, their families and friends</p>
The Financial Burdens of caregiving are affecting a large and growing part of the unpaid health care environment, especially in working class and poor families	There is a need for government supplements through grants or tax breaks and community-based fundraisers to help impoverished caregivers
Women Bear a Disproportionate Amount of the Caregiver Burden	Community and government organizations should implement public education campaigns to alter the faces of caregiving in families to include those of caring men
Age-Appropriate Supports for Children are necessary to help them cope when they are ill, when they are a family member and even when they become caregivers themselves	More professionally staff and trained volunteers are needed
People from Diverse Ethnic Communities require special considerations in the provision of caregiver supports, especially in their languages and with respect to cultural norms and values	All organizations need to assess their understanding of the cultural and ethnic groups in their service areas, develop links with ethno-specific organizations and review program delivery methods to more effectively serve those diverse

	communities
Collaboration with Service Organizations, Community Organizations , faith communities, volunteers and caregivers will be increasingly necessary to educate the general population about the importance of involvement in caring for others, including the self, governments and political members of the overwhelming burdens facing caregivers	Enhanced planning in LIHNs, and all levels of government to coordinate with service providers is needed
Funding to Develop and Enhance Group Support Initiatives to help the growing numbers of informal in-home caregivers who will be caring for the aging population of baby boomers	Must be provided by the health system to community, health and social service organizations, needing increased numbers of case managers/coordinators, counsellors, educators and advocates
Caregivers Need a Voice to 'tell it like it is' and to improve the sensitivity and clarity of communications with health professionals and institutional staff who are paid to care for their family and friends	Opportunities to be heard need to be made available to caregivers by health organizations through workshops and online messages

PILOT PROJECT: ENHANCED EXPRESSIVE ARTS FOR CAREGIVERS

In accordance with the project proposal commitments, it was necessary to take one of the most significant results and determine a relevant Pilot Project that was doable within the time and fiscal restraints of the project. The purpose of this phase of the project was to test and evaluate a model that would improve supports available to caregivers.

Based on Hospice Toronto's successful experiences with expressive arts therapy and group work, and given the noted restraints, the Advisory Committee agreed to invite caregivers to attend a pilot session conducted by an expressive arts therapist.

On January 23, 2010, 14 caregivers who had participated in the study and had agreed to be involved in a future pilot attended an expressive arts session.

The session featured a variety of modalities: group non-verbal expressions, small group visual arts creative works and guided meditation exercises.

We asked participants what they found was **most helpful** about the expressive arts group caregiver session. Their replies centered on the spirit of the group, the “coming together as one,” cooperating, inter-acting, connectedness, creating and sharing with people who came from “similar situations” and “it allowed me to re-work my grief.”

Most participants highly valued the session, calling it: “wonderful; I felt safe and shared much more than I would normally.”

OTHER PROJECT OUTCOMES

The development and distribution of the “The Hospice Resource Package,” a “what-to-do” checklist for survivors as well as a checklist to help children cope with the dying and death of a loved one were a direct reflection of the expressed needs that a high number of caregiver participants, would have liked but did not receive. Other comments included a need for specific education and assistance with navigation of the healthcare system. These will be used as companion documents with this report and have been and will continue to be an education/navigation resource/tool for clients and caregivers.

The documents are:

- *A Caregiver Resource Guide* lists local community services
- *What to Do When Someone Dies* is a checklist of organizations to contact and actions to undertake after death
- *When a Child’s Loved One Dies* describes actions to undertake in order to support children coping with the death of a loved one

CONCLUSION

The final conclusion resulted in the development and facilitation of an enhanced Expressive Arts Group and a Hospice Caregiver Resource Package that integrated the expressed needs of the majority of participants reflective of those supports they would have like to have had but did not receive. Results demonstrated that access to a caregiver support group, being listened to; learning strategies for self care, system/disease specific education and assistance with navigation of the healthcare system were needed.

The heart of this study was based on the premise that individuals frequently have little or no choice in their taking on the role of being the “caregiver.” Therefore it was our intent to learn rather than assume what those needs may be. This report (and the project), were not intended as an empirical research based study but was a starting point (at this point in time) for capturing data and formulating information to be used to inform and for planning future caregiver support initiatives.

A number of our participants’ stated that they wished they had been listened to and had had more of a voice while being a caregiver. It is our hope that being a participant in the “New Horizons Project” in some way accomplished that.

We would sincerely like to thank our participants’ for not only giving of their time and their stories for this project but for making such a difference in their loved ones life by being their caregiver. This report is dedicated to each one of you.

As a caregiver participant so eloquently stated, “I found care giving to be very nourishing to my soul. It felt so good to help another person and to be there for them, no matter how small, whether it was listening or helping around the house. It reinforces the fragility of life and has had an impact on how I live my life and the choices I make.”

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FOCUS GROUPS AND EXPRESSIVE ARTS PICTURES



“Being a participant in this project gave me the opportunity to share and validate my care giving experience. The focus group session was very heart-felt and informative. Thank you!”