



**Making a Difference:
Exploring the Experiences & Needs of Male Caregivers
May 31, 2011**

EXECUTIVE SUMMARY/ABSTRACT

Research is now challenging the assumption that men provide minimal caregiving service. This project was designed to explore the experience and needs of male caregivers inclusive of senior caregivers and to delineate any gender, cultural, or social barriers to men assuming a caregiver role. This project followed a qualitative survey approach, asking open-ended questions in focus groups, individual interviews, and through an online survey. We marketed to caregivers inclusive of seniors (55+) who included Caucasian, Aboriginal, and Chinese Catholic men, hospice volunteers and caregivers associated with several different disease-specific support organizations.

The men in this study reported some negative impacts of caregiving, but the strongest emphasis by far was on caregiving's positive aspects, which generally coalesced into four major themes: A strengthened emotional connection with the person they cared for; a deep satisfaction with their ability to help; an increased spiritual or philosophical outlook on life; and a strengthened (Aboriginal, Chinese Catholic) or transformed (Caucasian) self-identity. Men can and do step forward to provide quality care for their loved ones, and once they take on the responsibility their care has a distinctly male perspective that can be both effective and supportive, and provide as many benefits as challenges.

BACKGROUND

The Canadian Caregiver Coalition (2003) defines caregivers as family members or friends who provide ongoing care and assistance, without pay, to those in need of support due to a physical, cognitive, mental, chronic or terminal health condition. Hospice Toronto assists family caregivers by providing in-home volunteers to families who need respite or companionship. There has long existed in the medical field an assumption that women in general take on a much greater burden of caregiving than do men, seen in three distinct patterns: more women than men provide care within families; women provide more intimate care (bathing and medical tasks), as opposed to the impersonal tasks (managing finances and yardwork) that men provide; and women provide more emotional support than men. It appears this gender bias dissuades men from being caregivers and moves them to the periphery of most caregiver circles.

Kramer (2002) states that although caregiving encompasses a wide arena of qualities and activities it is nearly always defined as a feminine role. Often overlooked in the literature and research on caregiving are the varied roles that men fulfill beyond the financial one. On a practical level the assumption that caregiving is solely women's work can drastically reduce the effectiveness of families to provide care for longer durations, either by limiting the role of available men to impersonal tasks, or by limiting the role of caregiver to women.

Research is now challenging the assumption that men provide minimal caregiving service. Recent surveys suggest a significant percentage of caregivers are male. Statistics Canada (2003) reports that 10% of all men are caregivers, approximately 1.5 million men. Some researchers have estimated that 40-44% of all family caregivers are male (Ducharme, F, 2005), while another study estimates that 30% of *in-home* caregivers are men (Kramer 2002).

PROJECT GOALS

This project was designed to explore the experience and needs of male caregivers; to determine whether common assumptions about male caregivers (such as male caregivers provide only impersonal tasks like

housekeeping) were based in fact; and to delineate any gender, cultural, or social barriers to men

assuming a caregiver role. We hope this study provides us with new ways to support men who assume a caregiver role in their families, and new ways to recruit, train, and support hospice male volunteers.

LITERATURE REVIEW

In order to better understand the unique and direct personal experience of being a male caregiver, we looked specifically at qualitative research on male caregivers. Qualitative studies are designed to explore the personal experience in depth, and so requires relatively few respondents. The four qualitative studies we found are typical in this regard. Respondents numbered in the teens for three studies (Bidgood, 2002; Harris, 1993; and Sanders & Power, 2009). One study listed only four respondents (Black, Caruso, Schwartz, 2008) that they chose to interview in depth out of a larger study of 60 men. Most respondents were elderly men who were long-term caregivers for their spouses, and none of the studies examined potential differences between cultural groups.

These four studies present two key findings. First, the studies challenge the popular notion of male caregivers providing only limited, relatively impersonal tasks. Male caregivers in these studies provided the same level of personal care as female caregivers. Second, the respondents in one study reported they took on their caregiver role out of love for their spouse, rather than out of a social expectation, which was more commonly reported by female caregivers. These studies also point out several aspects unique to male caregivers that grow from their identities as men:

- Male caregivers more frequently report pride in their caregiving ability than women do.
- They express a strong commitment to protect and advocate for their spouse, preserving their dignity as well as keeping them safe (Sanders & Power, 2009; Bigwood 2002).
- Two studies noted men's concern with control, whether protecting their spouse's control and dignity, or struggling with a lack of control in the face of disease progression (Becker 1997; Sanders & Power 2009).

- Four studies report on men's reliance on past work skills and habits to help them manage new caregiving tasks. Skills include managing resources and working within systems as well as mastering specific tasks (Russell 2008; Braithwaite 1996; MacRae 1998; Perkinson 1995).
- Four studies noted the high value men place on learning about the disease as a way to cope with the high demands of caregiving (Harris 1995; Kramer 2000; Mathew, Mattocks, Slatt 1990; Bidgood 2002).
- Several studies note the unique negative impact on male caregivers, including lost wages and stalled careers. Russell (2008) also reports men had more trouble than women in accepting the long-term or permanent nature of their situation.

Decline in physical and emotion health was reported in a number of caregiver studies of both men and women (Burton, Schulz, Jackson & Hirsch, 2003; Harris 1993; Micka, 2006), but other studies found male caregivers experience fewer adverse health consequences than women. Women describe a higher caregiver load and more caregiver strain than men reported for themselves (Brazil, Thabane, Foster, & Bedard 2009).

One limit to the current research as noted in the four studies we examined is the lack of diversity of cultural representation of elderly caregivers, giving us only one cultural perspective and one social perspective on caregiving. Toronto is a culturally rich and diverse city, with families and volunteers belonging to many different ethnic and religious communities, leading us to question how the caregiver experience might be influenced by culture.

The second limit of the said studies is the small number of people who were interviewed for the qualitative studies, raising the question of whether these results will hold true for larger groups of male caregivers.

QUESTION DEVELOPMENT

Questions remain about male caregivers, including social and cultural barriers to seeing men as caregivers,

the willingness of men and women to accept men as caregivers, and the challenges facing men who take on the caregiver role. After careful consideration Hospice Toronto narrowed the field of inquiry to an open exploration of the direct experience of male caregivers from their perspective. This inquiry allowed us to expand the existing research of male caregiver needs farther into the community, and into communities beyond Caucasian married men. Because of the relative paucity of literature on male caregiving needs and experiences, Hospice Toronto decided to continue a qualitative approach to this research, asking open-ended questions to allow the greatest possible range of responses.

DATA COLLECTION

We collected data through three distinct routes: Focus groups, which were facilitated by a male professional social worker, with a female researcher recording the data; individual interviews for those who were not comfortable sharing in a group setting; and an online survey for anyone who was not able to attend a focus group. In each approach the same questions were asked in the same order, with minimal direction from the facilitator. Additional questions were asked only occasionally for clarification of specific words used. This approach allowed the greatest number of methodology options to meet shifting needs while maintaining the integrity of the inquiry.

The online survey included the same open-ended questions as the focus groups, allowing as much room for responses as respondents needed. It was marketed to two religious organizations, agencies that provided caregiver and family support for specific diseases, and to friends and family members of Hospice Toronto staff.

Researchers also marketed the online survey to several agencies that serve people with long-term care needs from chronic illnesses such as Alzheimer's Disease, Parkinson's, and Multiple Sclerosis. The result of this strategy led to a significant difference in caregiver responsibilities between the focus group and online respondents:

Length of caregiving role in years:

Years	<1	1-2	2-4	4-9	10+	total
Groups	4	9	7	7	6	33
Online	1	4	1	8	13	27
TOTAL	5	13	8	15	19	60

The online respondents reported significantly more instances of very long-term caregiving, sometimes lasting a decade or more. They reported doing more hands-on medical tasks, including suctioning and wound care. They were supported more often by personal care agencies such as the Community Care Access Clinic (CCAC).

It should be noted that the online respondents were the only ones who responded privately from their own homes. They were not exposed to/influenced by other people’s narratives like the men who participated in focus groups, making their data less reliant on social norms.

The focus groups were marketed to hospice volunteers who had previously been a personal caregiver, and to several organizations that support caregivers for people living with specific illness (Cancer, HIV), as well as two organizations that support people from the Aboriginal and Chinese cultures. Data was collected by taking notes on a flip chart in each group to let respondents see what was being noted. Each group was also recorded and played back at a later date to fill in any information that was missed and then subsequently erased.

The Chinese group was conducted as individual interviews at their request. The interviews were conducted in Chinese by a male bilingual Chinese social worker, who then translated their responses to English for the principle researchers. By partnering with a broad range of communities and agencies we were able to strengthen existing research while seeing more clearly the culturally-influenced challenges and rewards of caregiving.

INITIAL DEFINITION OF CAREGIVER

From the beginning of this project researchers were surprised by the number of men who had questions about the definition of caregiving. Many men who were approached to participate in this survey initially declined, stating they were not sure they met the definition of a caregiver. Several commented, “I’m not a

caregiver, I just helped out.” One man declined to call himself a caregiver because he did not provide direct, hands-on personal care, even though he was involved daily with medical decisions, financial matters, and managing care from a distance. For the purpose of this study researchers defined caregiving broadly, taken from the Canadian Caregiver Coalition (2003). Men were assured that caregiving duties could include helping from a distance, and were encouraged to complete the survey.

RESPONDENTS

Hospice Toronto and every partner agency had difficulty finding men who were able and willing to participate in the focus groups.

Overview of Groups: Dates, locations, # expected, # who actually attended.

DATE	LOCATION	EXPECTED	ACTUAL
JAN 26	HOSPICE VOLUNTEER GROUP	4	4
MARCH 2	HOSPICE VOLUNTEER GROUP	6	5
MARCH 8	ABORIGINAL GROUP	10-15	5
MARCH 12	HOSPICE VOLUNTEER GROUP	4	3
MARCH 16	DISEASE AFFILIATION GROUP	10-12	6
MARCH 23	CHINESE CATHOLIC GROUP	15-20	7
APRIL 29	DISEASE AFFILIATION GROUP	3	3
	GROUP TOTALS	52 - 62	33
	With 27 online respondents	79 – 91	60 final count

Three organizations predicted 10 to 20 respondents for their groups, but the total final groups averaged less than 5 (4.7) participants.

Three groups affiliated with hospice volunteers, total members: 12

One group of Aboriginal respondents, total members: 5

One group of Chinese Catholic respondents, total members: 7

Two groups affiliated with specific disease organizations, total members: 9

Online survey with total respondents: 27

Total respondents: 60

DEMOGRAPHICS

The research was designed initially for senior caregivers, but later expanded to include caregivers of any age. Of the 57 people who gave their current age, over half (34) were over 55 years old.

Your Age Now:

Current Age	Under 30	31-40	41-54	55+	total
Groups	1	3	8	17	29
Online	1	0	10	16	27
TOTAL	2	3	19	34	57

However, their age at the time they were providing care was significantly younger, with 38 of 60 respondents falling in the age range of 36–64.

Age when you became a caregiver:

Age	Under 20	21-35	36-54	55+	total
Groups	4	7	18	4	33
Online	1	8	17	1	27
TOTAL	4	15	38	5	60

Cultural/ethnic identities:

While respondents were invited to identify their cultural heritage by any criteria they wished, researchers found distinct differences between the major cultural groups represented: Aboriginal, Caucasian, and Chinese and Asian/Pacific Islander. By design the Aboriginal and Chinese groups were interviewed separately. This report will compare these broad cultural groups instead of looking more closely at ethnic and religious differences for two reasons. First, our goal was to explore differences at the broader cultural level, looking for how Aboriginal, Chinese Catholic, and Caucasian men approach their role of caregivers, as well as how caregiving impacts their lives. We did not partner with organizations serving particular ethnic or religious Caucasian communities, such as the Anglican or Italian communities. Instead we focused on the larger distinction of culture.

The second reason for not differentiating between the specific groups within the Caucasian culture is our recognition that the rich diversity within the Chinese and Aboriginal cultures was not represented. Western culture generally allows for great distinction among Caucasian people, which is a privilege few

non-Caucasian people enjoy. Our Caucasian respondents identified themselves by their ethnicity, their religion, their socio-economic status, and even the type of work they performed (middle-class, Manitoban, Anglican, Jewish), while our Chinese Catholic and Aboriginal respondents generally identified themselves by their race alone. We make the distinction of Chinese Catholic because the particular group of respondents we invited to participate were part of the same group. In general the ability to make fine distinctions between religion, ethnicity, and socioeconomic status is not available to Chinese and Aboriginal respondents, even though such variations exist in those cultures as well. Currently the distinction most recognized and used for non-Caucasian people in Canada is that of race.

Of the disease-specific support groups (HIV/AIDS and Cancer), seven (88%) identified as Caucasian and two (22%) identified as other than Caucasian. Of the online respondents, twenty-six (96%) identified as Caucasian, and one (4%) identified as other than Caucasian.

Of the hospice volunteer respondents, 100% identified themselves as Caucasian.

Of the Aboriginal respondents, 100% identified themselves as Aboriginal.

Of the Chinese group, 100% identified themselves as Chinese.

Apart from the Aboriginal and Chinese Catholic groups, the study was not designed to match respondents' cultural backgrounds with their specific answers. Therefore comparisons between Caucasian, Aboriginal, and Chinese respondents is based primarily on the three hospice volunteer groups that identified as exclusively Caucasian.

Finally, many men in the group of HIV/AIDS caregivers were also living with HIV. This gave them a different perspective from other respondents on the responsibilities and emotional impact of being a caregiver that we will discuss further down.

DATA ANALYSIS METHODOLOGY

The researcher analyzed the data from each group separately, and treated the online respondents as one 'group.' Raw data was comprised entirely of direct quotes from participants. Participant responses were

categorized first by the question they answered directly, such as ‘what did you have to do as a caregiver.’ The data was then grouped by similar responses. For instance the responses to this first question often fell into several categories in each group: practical tasks, emotional support, personal cares. The researcher did not attempt to find or create the same categories for each group, and instead followed the raw data.

Each group moved through the questions at their own pace. Some groups moved naturally through the progression we had designed, offering insights that answered the next question on our list before we had asked it. A few people answered earlier questions only later, responding to a later question that (perhaps) allowed them more emotional room to answer the first. This was most apparent with the questions: “was there anything you were asked to do as a caregiver that you were uncomfortable doing?” was often answered in the negative, but some discomfort did become apparent in their response to the next question, “were there any limitations/challenges?” Some men were more comfortable either perceiving or expressing an internal discomfort as an external challenge or limitation. We will discuss these findings in more depth further on. If a man identified his own personal discomfort with a caregiving task as a challenge or limitation, the researcher moved to that response to the category of discomfort. This happened occasionally but not often enough to reach significance.

The data, now collected into categories, were then compared across all groups to discover themes, similarities, and differences between the groups. We found strong consistency between the focus group and online respondents with similar issues, concerns, and strategies being raised in each. These similarities between groups increased our confidence that individual group dynamics were not unduly influencing our data.

We also found several significant differences between the three cultures in some of their responses. For the purposes of comparing across cultural groups we compared the hospice volunteer, Aboriginal, and Chinese Catholic groups, as they were all monocultural in make-up, before turning to other respondents for confirmation.

This report will elucidate the differences found, but is unable to draw conclusions about why such differences exist. The project was developed as an extended qualitative survey. The questions are open, allowing for a range of responses, but we offered no follow-up questions and did not explore the reasons behind any initial description or response. We will leave the question of meaning for another project. For now it is enough to recognize that real differences exist between men and women, and between different cultural groups.

QUESTIONS AND EMERGING THEMES

Question One: How did you become a caregiver:

Researchers report that husbands are highly committed and strongly devoted to their wives (Sanders & Power, 2009). Harris describes a theme titled “the labor of love,” which was characterized by deep emotions that husbands had for their wives and the loving intimacy that was shared between them. Other findings suggest men enter the caregiving role because of a lack of alternative options and a strong sense of duty (Bidgood 2002).

This project confirmed the major reasons for men becoming a caregiver: First, they had strong emotional or family connection to the person needing help, as this man did for his wife: “My wife was sick. Of course I had no choice. Some might have walked from that but we were married, committed, loved each other and had a son together. So, that’s the life.” Second, they were stepping into a caregiving role because no one else was available, seeing themselves more like back-up than the first responder, as this man describes, “His wife had left, given up on him. My cousin couldn’t be there all the time. I was the only person in town that she could trust and pay. I was the only option. I was a necessity.”

Finally, many spoke about their feeling of love for the person needing help. While it was clear the respondents we spoke with all loved the people they cared for, the men who responded online emphasized strong emotional reasons for providing care with answers such as the simple statement, “[I] fell in love.” Doubtless love figured into each caregiver’s decision, but the online group stated love more explicitly as

their primary reason for becoming the caregiver.

The Chinese Catholics placed more emphasis on social expectation than the other groups. As one respondent described, “My experience as a caregiver started when my mom became ill. As a child, it is my duty to care for her. During her illness, I felt that it was my duty to care for her. One man in the Aboriginal group emphasized the human condition of caregiving: “I was taught you’re born needing help cleaning up the shit and when you’re going out you need to clean up the shit too. No shame in that, it’s part of the continuity of life.”

Question Two: As a caregiver, what did you have to do?

Sanders & Power (2009) listed several key tasks male caregivers provide including personal care; protector of self-esteem, dignity, and personhood; planner of activities, socialization, home maintenance and house-keeping. Our research showed most caregivers listed personal care as their primary task. A significant number spoke about their role as guardian and protector, which we discuss further down as advocacy. Caregivers also reported managing financial affairs as part of the general household managing.

We found no difference between the groups about the direct, day-to-day care they provided. From managing care while living farther away, to providing around-the-clock total care, they took care of whatever needed doing. They provided personal cares like bathing and helping with mobility. They cooked and shopped and did laundry, took their loved ones to medical appointments and talked to the doctors. Brazil et al found that male caregivers were significantly more likely than female caregivers to receive help with personal care, like bathing and toileting, from a friend or other family member (Brazil, Thabane, et al 2009). Most of our respondents, however, spoke of providing all necessary cares themselves, including personal care tasks, as this man describes in caring for his wife:

“[I] supported her emotionally and instrumentally from time of recurrence to her death over a 30 month period. Attended medical appointments and chemotherapy sessions, and increasingly helped her with self-care as her disease progressed, including daily changes of dressings/bandages, filling

prescriptions and giving medications, feeding and helping with personal hygiene as necessary. She died in my arms.”

The emotional aspect of caregiving was not reported by our respondents with as much frequency as the practical tasks, but it always appeared and was considered a vital part of caregiving. They listened, shared stories, held hands, provided emotional support and humor and favorite foods. These tasks were devoted to the emotional life of the person they cared for, to help improve and preserve the person’s sense of dignity and pleasure in daily life. As one man described, “It was a lot of hanging out, spending time, talking with him, not leaving him alone. I wouldn’t want to be alone. Time spent like this is just as important as the physical.” Another man described his goal in being with his wife was less about her comfort (although that was vital) and more about her emotional well-being: “Most of all, keep her company and make her laugh and love her life.”

Emotional support was also apparent within some of the tasks they performed:

- “Whatever she felt like eating. I found I was willing to do anything, get anything she wanted. Whatever she wanted, I would go and do it. Even if it was KFC and she had hated KFC.”
- “I was bringing him beer and drinking with him to keep him company.”
- “I showed him how to use make-up to cover the lesions.”
- “I took her shopping for new clothes, and to the hair salon.”

Most found the emotional support the most important part of caregiving, but one focus group discussed the difficulty they initially had shifting their attitude from a more task-oriented approach. As one man observed, “I was not as supportive in retrospect as I could have been, or as I eventually became. I focused on things more tangible than the emotions [saying] ‘It’s time to take your medication. It’s time to eat, you have to eat! Time to eat!’ I was harassing her rather than supporting her.” His comments echo one study which states men will sometimes prioritize the tasks of caregiving over the emotional needs of the person being helped (Calasanti & King, 2007.) The man in this group was able to recognize his actions and change his approach to caregiving. He taught himself to slow down and trust his wife’s changing

appetite, and found a new level of intimacy with her.

Sanders & Power (2009) found that men often advocated for their dying loved ones and themselves. Our research found five of the seven focus groups and the online respondents all noted some form of advocating for the people they were caring for. Not every man reported fighting for better care, or described himself as an advocate, but the idea of fighting for a loved one was mentioned by at least one person in each of five groups and within the online responses. Such advocacy included arguing with doctors over care decisions, pushing to get the right level of care, fighting about insurance coverage, and pushing for more help in general. Here are a few quotes among many that center around the idea of standing up for their loved one's rights.

- “Now that she's in a nursing home I have to make sure she's given the care she needs.”
- “Being an advocate through the system. A voice for them to help access services.”
- “Medical advocate, research illness, take to appointments...”
- “I fought and screamed and yelled to get a few hours per week from the CCAC...”

Most took pride in their ability to fight for what was needed. As one man described himself, “I'm a warrior type, [meaning] ‘get it done!’” And several men came up against inevitable limitations. One admitted that fighting did not always work. “When I came to a ridiculous situation I talked to people and explained how their rules were hurting my mother. It didn't help, because they didn't care and they couldn't do it differently anyways. She still suffered.”

One man reported feeling uncomfortable with arguing. “It was kind of a shock to realize I had to do this. I always thought they [paid caregivers] were caring, that caring was their forte, but some aren't good at it”

The only two groups that did not mention any form of advocacy were the Aboriginal and the Chinese Catholic groups. This is a significant difference found between the three cultures, and the difference appears to run deeper than the definition of any particular word. The idea of fighting or pushing for needed services simply didn't arise in the Chinese Catholic or Aboriginal groups. They expressed the

same helplessness and frustration the other groups described, but did not then describe actions they took to address the situation. No person in either of these groups mentioned any form of fighting, arguing, pushing, questioning, or asking repeatedly for help.

Here are two examples from two different respondents, the first Caucasian and the second Chinese Catholic. Both men watched a parent suffer with unaddressed pain and felt helpless to fix it. This first quote is from a Caucasian man talking about his mother's pain: "I had to push the doctors to treat her. They thought it was too early in this stage of cancer to have this much pain. I was bringing her back to the hospital again and again, and finally they gave in and she was started on morphine." This man was upset and frustrated that he had to push so hard to get the care his mother needed, but he also expressed pride in his ability to fight for her.

The second quote is from a Chinese man as he describes his helplessness watching his father in pain. "Often, I felt so helpless with the situation. Particular, when he was in pain. Even the doctor ordered him pain medications already; the medication was not really helping... I really wanted to help yet there was nothing I could do...I really did not know what to do [ellipses inserted by original interviewer]." In the second example we hear the same frustration and helplessness, but no mention of pushing medical professionals to get more medicine.

It is beyond the scope of this study to speculate on reasons for this difference. The difference may be due to nothing more than the personalities of the individual respondents, but it is worth noting here.

Question Three: Was there anything you were asked to do as a caregiver that you were uncomfortable doing?

Most respondents in this project did not report discomfort with the more personal tasks of caregiving. A few mentioned the discomfort of cleaning up after bowel or bladder accidents, but for the most part these cares did not cause much concern.

A few people remarked on personal cares feeling like crossing a line of privacy, particularly when

caring for a parent. One man felt uncomfortable providing personal care to his mother-in-law, concerned about her sense of dignity. “It was very awkward changing my mother-in-law. If I could pass that along I would. I had a sense of her dignity and didn’t want to trespass on that. As long as she could help herself or someone else could do it, then I passed it on. But if I was the only one and my wife wasn’t around then I would have to and it was awkward.”

A surprisingly common response throughout the groups was that no particular task made them uncomfortable. Even in the more personal tasks, it is interesting to note how few men felt uncomfortable providing personal cares to their loved ones. Out of 26 online respondents to this question, 16 reported no discomfort with any aspect of caregiving. Here are a few samples from both online and group respondents:

- “At first I was a bit overwhelmed by the intimacy of caregiving, but I came to treasure it.”
- “The fact that we were husband and wife, I never felt anything uncomfortable or embarrassed about it. I never thought of the gender difference while providing care.”
- “There wasn’t too much I wouldn’t do. She was my mom, for one thing!”
- “I did it because it had to be done and I didn’t think anything of it. But probably I would feel uncomfortable if it was for someone I didn’t know.”

The greatest discomfort came from being asked to deal with unfamiliar and complex medical tasks, without enough training or education. Several had to monitor IV sites for signs of infection, administer injections, and care for catheters and IV pumps. This work made them extremely uncomfortable at first, most felt unsure and anxious about inadvertently hurting the person they loved, and not having enough training or support from the medical profession to do what they knew they had to do. One man described the perils of administering needles. “I was petrified, the first time I had to do it. I didn’t know how far to put the needle in, which direction, whether I’m doing it right, whether there was going to be air beneath the skin.”

Several people spoke of the fear of not being able to provide good enough care in general, and they worried they would not be able to do what they knew needed to be done:

- “Most discomfort rose from my own sense of incompetence.”
- “I was worried because I felt like I had her life in my hands, which was scary.”
- “I think the whole aspect being a caregiver frightened me in the sense am I going to be sufficient enough? Am I going to follow through with procedures? Am I going to have the guts to follow through with it or get sick in my stomach? You’re always thinking of that.”

The question of what should take precedence at the end of life—emotional needs or physical needs—was raised a number of times. Several people noted a shift they made from keeping their loved ones healthy to keeping them satisfied. One man spoke of the struggle over whether to provide alcohol to his uncle and drink with him to keep him company—something both knew would bring his loved one pleasure in his last days but was also extremely detrimental to his health. The caregiver decided to honor his uncle’s emotional needs over the health concerns, but it was a complicated emotional decision. “I knew it wasn’t good but I wouldn’t tell him to stop because it’s not up to me. I did feel guilty about drinking with him. That was difficult. But really there was no stopping him. He’s going to drink whether I’m with him or not.”

One focus group reported no discomfort at all. Every single person reported he had had no feelings of discomfort in the caregiving role. Some of the challenges and limitations described in the next section, however, clearly led to feelings of fear and discomfort, leading researchers to wonder if respondents were defining discomfort as something that would stop them from performing a particular task.

Question Four: Were there any limitations/challenges?

Differences emerged between Caucasian caregivers, and Aboriginal and Chinese caregivers in the challenges they described. Caucasian caregivers described the limitations and challenges more often as external forces that impeded their ability to provide good care. They reported a consistent frustration with the healthcare system, including lack of coordination, lack of needed services, and uncaring or

disinterested staff. People who considered themselves advocates were mostly advocating to the healthcare system on behalf of their loved ones. While several noted they understood intellectually the limits of the healthcare system, they hadn't realized how much it could negatively impact their daily lives. Some described harrowing nights when their loved one's pain was not well controlled and they needed to push medical staff to give enough pain medicine. Sometimes the stress of feeling not competent to do medical tasks led to increased anger at the healthcare system. "I had a phobia about needles, but I had to learn how to give injections because the caregivers (paid caregivers) couldn't do it for legal reasons. It felt like care by lawyers!"

The Aboriginal group described their limitations and challenges as almost entirely internal, rather than seeing challenges as something external they had to meet. Group members agreed with each other about the lack of dependable transportation services, but they were more intent on their lack of time to do more, and their sense of guilt if they had to leave their loved one alone. An Aboriginal man who provided care during the day and worked at night listed as a challenge the trouble he had focusing on his work when he was away from home: "It's hard not to be thinking of him when I'm not there. As human beings we are emotional. You get to know someone, you care for them. It's natural, human." He did not mention any concern with unreasonable work demands or the demands of his loved one, but wished instead he had more time to do more.

There were a number of comments in all groups on the lack of control when living with illness. Some expressed concern they could not fix the situation or find a way to ease their loved one's pain, which led to a feeling of helplessness.

- "There is a certain level of frustration if you can't help the person for some reason. You can't help the circumstances."
- "You want to help but you can't wave a magic wand. It's their own personal work."

A significant number of Caucasian focus group respondents and a few online respondents described

feeling frustrated at a lack of control in their relationships. They experienced discomfort letting someone else be in charge and make mistakes they might not have made, or take actions they would not have taken. Their words draw a picture of a subtle shift in relationship dynamics that can occur with illness or disability. Most of them describe a relationship between a male caregiver and a woman, whether the woman was the one needing care or was the primary caregiver they were trying to help.

- “I had to realize I am not in control of her decisions...”
- “The expectation of husband was I would be participating. But if I expressed my intentions and they weren’t consistent with what she would have done, then I had to take a back seat on my opinions. I had to follow my wife.”
- “My mother was stubborn, cantankerous. She wouldn’t go to the doctor, didn’t want to do anything that I thought she should do, reasonable people would do to take care of herself.”
- “[I] try to help, [but] realize I am not in control of her decisions to stay in a dangerous environment.”
- “She was a proud woman and at times important issues would get ‘swept under the carpet,’ as they say.”
- “lots—limitations in my skill and patience, and limitations imposed by my mom and her illness.”

The one man who spoke of this dynamic with another man (a former partner) noted how his former partner pushed back at him, “I had to watch over him... I became his mother—he used to curse me out for it! I had to be careful. I realized I was directing him. He was an adult, and had choices that only he could make.”

The group of Chinese Catholic caregivers described this shifting dynamic as part of a more internal challenge. Two spoke of a similar frustration with someone else setting their schedule for the day, but they saw this challenge as coming from their own wants, and described learning how to put the other person’s opinions first. As one Chinese Catholic man described it, “I find it difficult not to do things ‘for her’ but in reality that was based on my ‘own needs.’ I needed to remind myself not being selfish and egotistic. I need

to learn how to meet her wherever she is at.”

This shifting power dynamic was not noted by the Aboriginal focus group. They spoke of their relationship with the person they cared for, but not in terms of power or frustration. The Aboriginal group was also the only group to spend time describing the positive attributes and personal histories of the person they cared for, giving the researchers a picture of the whole person. One man described with pride his mother’s return to school and her subsequent teaching of their native language at the women’s center.

Question Five: What helped you get through it?

Current research reports men are successful in caregiving roles through the use of outside assistance, self-education around disease progression and strong coping patterns (Harris 1993; Kramer 2000; Mathews, Mattacks, and Slatt 1990). While we examined the breadth of the outside help available to caregivers further on (see X) this section focuses on the latter question of coping strategies.

There were no differences between the groups in the ways men found to help themselves cope with caregiving. Men in the focus groups reported they relied on friends, family members, and professional counsellors for emotional support, “Friends. Just to have that one individual that’s willing to listen means a lot,” as one man noted. Some found community within the healthcare system, as one man reports: “When I looked at other patients who were going through the illness, I guess it gave me a sense of comradeship with other patients. Everyone needs help from each other.” Several people mentioned the focus group as a good time to meet and tell their story without fear of being judged. Groups also gave people a way to hear other stories and start comparing their work to others.

Most respondent also used agencies such as Community Care Access Clinic, non-profit and volunteer organizations for day-to-day care, depending on the level of care that was needed. Online respondents reported a much higher use of agency supports with a broader range of services in place.

They took their job seriously as men, relying on cultural touchstones about men’s work and men’s roles in the world to help them through the work. Every group reported a fair amount of self-talk to keep

themselves focused on the work they had undertaken. They often relied on common cultural messages related to gender. They told themselves ‘to be determined,’ to ‘get on with it,’ to ‘get it done’. As one man described, “Some things might have been challenging but help was needed so I pushed through, and then learned.” Another man described it as maturation, “I grew up quickly, learned I had to man up.”

They pushed themselves to keep their promise of giving care. One man described accepting “that when one takes responsibility for something, it’s just plain wrong to shirk that responsibility.” As another man put it, “I had to say to myself I have to be determined, I have to be stern stern, and I’m going to do it, no matter what. I’m going to do it to the best of my ability.”

But the most frequently noted coping was the way they reminded themselves of their purpose, and the love they have for the person they cared for. This was expressed most clearly as love by the online group. Of the twenty-six responses to this question, seven people listed love, devotion, or the strength of the relationship as what keeps them going. As one man answered, “My dedication to seeing my grandfather and my friends have as much quality of life as possible and the desire to see them to a peaceful death. My love for them.”

Many reported feeling a sense of pride, satisfaction and accomplishment, even gratitude for their ability to help their loved one in such an intimate journey. Those feelings helped them understand their work was important and needed and meaningful. The comments came from all groups and the online survey:

- “Knowing that you’ve done something good for somebody else, to help them prolong life, live a better life, even recover. That makes me proud.”
- “A sense of satisfaction that I could be there for her.”
- “Doing the best you could do.”

Spirituality played an important role in many of their lives, all expressed in different ways. One Caucasian man described himself as becoming a spiritual warrior through his caring for his mother. Several described a new or renewed interest in meditation and yoga, or joining a religious community.

While direct references to God were rare, several men in the Chinese Catholic group noted the importance of faith in God: “It is because of our strong faith in God and we lift everything to Him. It would be up to Him to decide how long she has to live and how long I can help her.”

For the Caucasian respondents the advocacy work they did also had a healing effect for them. For some the advocacy consisted of pushing staff to better meet their needs. Several joined volunteer organizations and continued working for the community. Helping others, making the system work better, growing new services and finding ways to help the community helped them find a new emotional balance. “We created a worldwide organization, running conferences, workshops, support groups, parents and caregivers coming together.” As one man noted, “I had to have my voice, and learned to fight the system for what we needed. Find solutions beyond venting and anger. I had to find a way to impact gaps in services; instead of submitting to the system, get knowledge to work it.”

While a few people described using drugs or alcohol as self-medication, or finding ways to vent frustration through physical exercise, most respondents did not. Some spoke of rewarding themselves at the end of the day with a beer or marijuana, but few described relying on drugs or alcohol for escape from their situation, and the ones who did also described their eventual decision to reduce their use and face their loved one’s illness more fully. As one man describes, “At first I couldn’t look at it when my mother got sick. Avoided it [through alcohol]. I am re-evaluating now what is important. Someone else’s needs are more important than my own—[it’s been a] huge change in me.”

Question Six: What impact did being a caregiver have on you? and

Question Seven: What were some of the positive aspects of caregiving?

The men in this study reported both negative and positive impacts, but the strongest emphasis by far was on the positive impacts of caregiving. I have collapsed these two questions into one section because so many people responded to Question Six with strongly positive statements. The positive impacts and aspects of caregiving were rich, and generally coalesced into four major themes: A strengthened emotional

connection with the person they cared for; a deep satisfaction with their ability to help; an increased spiritual or philosophical outlook on life; and for Caucasian men in particular, a sense of personal transformation.

A strengthened emotional connection

Many people described the pleasure, at times unexpected, of developing a stronger emotional bond with their loved one. As they spent time together they learned valuable insights from the people they were caring for. One man looked back with fondness on the days he cared for his elder, holding up those “memories of talking to that person in their latter days,” and feeling grateful for the “knowledge and wisdom they pass on to you.” Sons caring for parents found the time they spent alone with their parent gave them new insights into their parent’s character and gave them the chance to heal old wounds and express their love. “I liked getting to know the man who sired me, and realized how terrific he was. I could sit with him and he would talk to me, man to man.”

Men caring for spouses found ways to become more open to each other, more vulnerable as they shared fears, more present to their spouses’ emotions, all of which enriched their time together. “All this time putting on the brave face, being stoic, maybe I was keeping myself from falling apart. But I was keeping from her the sense of how important she was, and how scared I was. It made things a lot easier to just say I’m scared, I don’t want you to die, I wish you weren’t sick, I don’t know what I’m going to do once you’re gone. It changed our relationship for the better.”

A deep satisfaction with their ability to help

Sanders & Power (2009) found a clear sense of pride emerged among male caregivers that they were fulfilling a critical role in the overall care of the wives. Across all groups men described feeling proud, honored, and deeply satisfied with their ability to help their loved one. They felt a sense of satisfaction that their loved one was being helped, and a humble kind of pleasure that they could do such good. “Especially to a Chinese person, we have a long tradition of respecting the elderly and care for them. When you

actually have the ability to fulfill the role, you feel so happy. When you know that you have tried your best, given your best, it is a 'payback' to your parents." Several people were surprised and pleased to find within themselves a new courage and resilience as they cared for their dying spouse. As one man described, "It taught me I can have courage. I can be brave and do hard things in that situation. I have increased respect in my abilities to weather storms." A number of people noted their personal caregiving led them into the world of volunteering for others or into a new career of professional caregiving.

An increased spiritual or philosophical outlook on life

Many spoke of their caregiving in spiritual or philosophical terms, noting the fleeting quality of life, the reality of death, and the power of remaining present in each moment. They became more aware of the importance of love and relationship. Some took up meditation, began yoga, reconnected with their spiritual beliefs, or deepened their connection to their religious communities. As one man commented, "I may not be spiritual in the conventional sense, but for me there is a saying that I certainly subscribe to: This work we've been doing sure takes the wrinkles out of your soul!"

Many felt they received a new perspective on life and death, were able to think about death in a new way, as an important aspect of life. They came to a better understanding of their human limits and learned how to accept painful realities. "I had to come to inner peace with human suffering. I had to find a new level of being a spiritual warrior."

A personal transformation

Many people in the predominantly Caucasian groups spoke of their caregiving as being personally transformative in some way. They talked about caregiving giving them an opportunity for personal growth. One focus group participant put it into these words, "I felt more completely a man, in the sense that I knew what caregiving was about, and now I was completing another side of myself with emotional and psychological wholeness." As much as some were frustrated earlier over a loss of personal control, others

remarked that attending to another person's needs gave them a new kind of strength. As one man stated, "By helping others you get a perspective on your own life." And one man put it simply as, "I grew up," an observation echoed by many respondents.

This sense of transformation was the most important aspect of caregiving for those who described it. They felt grateful for this transformation, and felt they became better human beings. "It brought me into a kind of intimacy that I had kept away from in my life. I was eventually able to care for friends and family members in a more open way. It helped me understand a bit more about the fragility of life, and about my own mortality."

Three of the focus groups—Aboriginal, Chinese Catholic, and men living with HIV—did not report this same transformative quality of caregiving. Their caregiving gave them many positive benefits, but a personal transformation was not a part of those benefits.

The Aboriginal group, for instance, made no mention of growing up, maturation, spiritual development, or any of the other transformation language used by Caucasian men to describe their experience. Instead they focused on their ability to provide the care. As one man described, his satisfaction came from "knowing you did [the] best you could for that person. Knowing you were there for that person as long as they needed." They were glad and proud they could help, and they relied on spiritual and philosophical beliefs for coping like all other respondents, but they did not use the language of emotional or spiritual growth. Rather, they used language that described how to be a human being living in community. Their work affirmed their identity as a member of their family and community, as a part of the greater human family. They did what was expected of all human beings and were proud they were able to meet that challenge. This was expressed most clearly by one man who was lamenting the breakdown of this very social fabric. "[This is] my lament: We used to all have life volunteer roles for the community, to care for each other. We all had roles when the babies came and when we're going out [dying]. But now we're all scattered, we can't do that anymore. When my great grandmother went to the other world there were a lot of people [who] helped. There was community. We don't have that anymore."

Several men in the Aboriginal group considered their caregiving as real-life training for the next time they provided care to someone. They did not speak of their caregiving as a single episode in their lives, but rather as one more aspect of what it means to be a human being living in community. When asked for any positive impacts of caregiving one man said, “[It] gave me needed experience; sooner or later I will be helping others. This is not the only person you’re going to be helping out, someone else will need help too.”

The Chinese Catholic men were also more focused on the satisfaction and pride of providing good care than on any emotional or spiritual transformative qualities. They spoke about the spiritual implications and a new understanding of life’s meaning. One man noted, “I realized that life is so fragile and your loved one can be gone in an instance. I have learned that you need to treasure everything, especially the people that you know, because you may not be able to see your loved one ever again.” But statements such as these did not then link to a sense of personal growth or transformation, as the Caucasian men’s statements often did. Their caregiving did not challenge them to step outside of social expectations, but rather step up to meet the expectations of being the eldest, the child, the spouse. Their work affirmed their identity as the responsible one, a good son, a caring husband.

The Chinese Catholic respondents were the only other people besides the Aboriginal respondents to mention a possible future role as caregiver. One Chinese Catholic man spoke of how the work prepared him: “After all the care I provided for my mother, the pain and suffering, it was like a training exercise for me and better prepare me should I need to do it next time to care for someone.” He was looking ahead to another day when he might be expected to step up and provide care for another family member.

Finally, the men living with HIV also reported fewer instances of a spiritual, emotional, or personal growth transformation coming from their work as caregivers. Several spoke about their own lives with HIV as holding transformative moments, and their stories of caregiving were interspersed with stories of their own times of needing care. They expressed a sense of identity that was linked to this particular community.

The negative impacts were addressed much less frequently than the literature indicated, but a few concerns did echo the impacts found in our review. Four men out of all respondents mentioned work and financial burdens or missed job opportunities, which were noted in several studies (Folman, Chesney, And Chrstopher-Richards 1994; Wyatt, Friedman, Given and Given 1999). Often their comments were short, such as one online respondent who noted: “Had to take time off work, financial burdens.” A couple of these men noted this loss of work opportunity resulted more from their changing priorities, as one man describes: “I didn’t need to climb the career ladder, which was a good decision. It’s hard to be around people who focus on less important stuff. I have less patience with that.”

Eight respondents spoke of the emotional stress of caregiving at the end of a loved one’s life. They reported feeling “emotionally tired,” and noted how the stress they felt turned into anger and physical stress. One man described this interplay between stress, concern, and anger: “It was emotionally draining to watch my mother slip away. I held it in to the very end, tried to be strong for her but it was exhausting physically and emotionally. I felt angry, resentful at my mother for dying, and the other people in my family for not helping.” Another man describes the way his caregiving stress accumulated until it expressed itself in physical pain. “I was very tired, sad, frustrated, exhausted, [had] mental fatigue. A month after she died I had tremendous back pain for several days, crawling around on my hands and knees for five days. Amazing how it physically affected me only after she died.

Chinese Catholic men had a strong sense of social role expectations and obligations, and reported higher levels of stress in meeting (or failing to live up to) those expectations. One man described how he pushed away help from his family because he was convinced he was supposed to do all the care. Like women caregivers in previous studies [CITE], these men felt a social obligation to provide the care and to not accept help, which added to their stress. “I believe that I am the only one need to do everything. I really have difficult to ask helps from others. Whenever I could not do the thing I want to do frustrated and worried me.”

Finally, just three men from all the project respondents described feeling isolated from their friends

by the demands of their caregiving duties. They described it as a sacrifice of their own life, and a sense that caregiving had taken over their life. As one man described his caregiving as a youth, “It was like the world had stopped. I felt a breakdown of my social network. Other kids were out playing. It put me out of synch with others—it was tough for me.” But again this was not a predominant theme in the group discussions or with the online respondents.

SERVICE QUESTIONS

In addition to the facilitated questions and answers noted above, we gave each group member a paper survey asking three questions about community services and a paper evaluation the focus group discussion. These questions appeared online as well in the same open-ended format, giving them room to respond in whatever way they wanted. We asked them to list the services and supports they had received, to list what they had found most helpful, and to list what supports—if any—they would have used had they known about them. People were encouraged to list as many services as they wanted. Respondents did not answer every question, and some respondents didn’t list any services. Others listed several agencies, and each agency was counted separately. A few respondents reported ‘several agencies’ without giving any details and were counted as one response.

Where did you get your services or support? How did the services come to you?

Type of Support	Group Respondents	Online Respondents	Total
Medical system Hospitals, MD offices, aftercare services	7	8	15
Hospice, Palliative Care	4	3	7
In-home care CCAC, home care, SPRINT, private hire,	6	25	31
Informal support Friends, family, neighbors, church	13	5	18
Living facilities	0	3	3
Formal Emotional support groups, counsellors, social	8	2	10

workers			
No help		1	1
Total services noted	38	47	85

Because of the small number of services listed, and the relatively large number of focus group respondents who did not answer these final questions, we were not able to break down the number of agencies by specific groups. The online survey group listed more formal services than did the focus groups, but at this time we are not able to state why this should be so. We might guess that the number of long-term, complex illnesses the online respondents faced made it more likely they would access formal support agencies (CCAC, long-term care agencies). On the other hand, the difference between the online and group respondents can also be explained by the number of men across the focus groups who did not complete the final three questions about services.

Which of these agencies did you find most useful?

Type of Support	Group	Online	Total
Medical system Hospitals, MD offices, aftercare services, hospice teams	0	12	12
Hospice, Palliative Care	3	6	9
In-home care CCAC, home care, SPRINT, private hire,	5	17	22
Informal support Friends, family, neighbors, church	5	3	8
Living facilities	0	0	3
Formal Emotional support groups, counsellors, social workers	3	0	3
Other physical release, All are good	2		
None/ NA	3	5	8
Total services noted	21	43	65

The focus group respondents who did answer these three questions often listed emotional support

from friends, family members, church, and counsellors as most helpful. The online group listed 31 formal agencies they found most helpful, and most of those provided functional support rather than emotional support.

What is more surprising is the number respondents from both online and focus groups who answered the question with no, none, or not applicable. They were not able to list any support that helped them provide care. This response could have been connected to a number of explanations, but this study did not explore the question in any greater detail.

What services and support could you have used, but didn't get?

Type of Support	Groups	Online	Total
Hospice support Palliative/Bereavement	1	2	3
In-home care more hours, better trained, more caring staff	4	9	13
More family support	0	2	2
Better coordination of medical care	0	3	3
Better/more support for caregiver	1	3	4
Other financial, transportation, training	2	2	4
None/ NA/Not sure	3	7	10
Total services noted	11	28	39

With the final question the number of non-committal responses climbed. The number of people who reported no needs beyond what they managed to provide was significant. Ten respondents answered this question with 'unknown,' 'got all we needed,' 'not sure,' 'N/A,' 'nothing much was lacking,' and 'not sure what services were available.'

What respondents did note was the need for more functional support: better home care, better physical therapy training to keep their loved one at home, better day support, and better coordination of medical teams. They needed respite with the assurance their loved one would be cared for when they took

LIMITATIONS

This report includes several limitations. Because of the small number of respondents we are not able to generalize our findings to any community. While differences appeared between the cultural groups, we cannot say with any certainty if those differences came from culture, or from the specific individuals who agreed to participate. Group dynamics also may have led to different points being stressed in each group. Each group had a unique style and tone to their answers, as happens in any group setting. For instance, the Chinese Catholic men were going to meet as a group of about twenty people, but all then quickly changed their minds when one man requested a separate interview. In the end only seven people stayed long enough to be interviewed individually. We believe their sudden request for more privacy came less from cultural norms (as the group leader who facilitated the discussion was known to them) and more likely from the power of group dynamics.

Third, the focus groups were minimally guided by the facilitator, without additional questions except in rare instances of needing clarification. This decision kept the focus groups closer in tone to the online survey, but it did not allow researchers to develop or follow specific answers for their meaning. So while we noted differences in individual and community answers, we took care not to provide guesses as to why these differences exist. For now it is enough to note the differences and let them guide future research.

CONCLUSIONS

Russell (2008) points out that few studies have focused on men caregivers as the primary unit of examination. This project was designed to explore the experience and needs of male caregivers, and provides a starting point for exploring caregiving from a cultural perspective.

The data collected from this study was to provide Hospice Toronto with information on how to

develop best practices to support men (*all ages with a special focus on those who are seniors 55+*) who assume a caregiver role in their families, and new ways to recruit, train, and support male hospice volunteers. Rather than looking for the reasons men did not provide care more often, or the reasons women may be less willing to ask men for help, Hospice Toronto decided to focus on what kinds of care men could and did provide. We hoped to find culture and gender roles that could provide support and direction for caregivers, as well as the challenges so many have delineated in past studies.

This project confirmed earlier studies on how men become a caregiver: First, they had strong emotional or family connection to the person needing help. Second, they were stepping into a caregiving role because no one else was available, seeing themselves more like back-up than the first responder. Finally and perhaps most importantly, many spoke about their feeling of love for the person needing help.

Often overlooked in the literature and research on caregiving are the varied roles that men fulfill beyond the financial one (Kramer2002). While our respondents reported managing financial affairs as part of the general household managing, many more spoke about their role as protector or advocate for their loved one. Most of our respondents listed personal care as their primary task. The emotional aspect of caregiving was not reported with as much frequency as the practical tasks, but it always was described as a vital part of caregiving. They listened, shared stories, held hands, provided emotional support and humor and favorite foods. They devoted their work to the emotional life of the person they cared for, to help improve and preserve the person's sense of dignity and pleasure in daily life.

A surprisingly common response throughout the groups was how few respondents reported discomfort with the more personal tasks of caregiving. A few mentioned the discomfort of cleaning up after bowel or bladder accidents, but for the most part these cares did not cause much concern. Out of 26 online respondents to this question, 16 reported no discomfort with any aspect of caregiving.

Their greatest discomfort came from being asked to deal with unfamiliar and complex medical tasks, without enough training or education from their healthcare teams. They felt unsure and anxious

about inadvertently hurting the person they loved but still knew they had to do the task, that there was no one else to do it for them.

One important distinction we found between cultures centered around questions of power and advocacy. Sanders & Power (2009) found that men often advocated for their dying loved ones and themselves, something our project confirmed with Caucasian caregivers only. The importance of advocacy was not noted by the Chinese Catholic or Aboriginal groups, leading us to wonder if it is a culturally-based phenomenon. People who considered themselves advocates were mostly advocating to the healthcare system on behalf of their loved ones. Our Caucasian respondents stated that the advocacy work they did had a healing effect for them.

Every Caucasian group included respondents who described feeling frustrated at the sudden lack of their own control in their relationships, in contrast to the Aboriginal and Chinese Catholic groups. Caucasian men experienced discomfort letting someone else be in charge and make mistakes they might not have made, or take actions they would not have taken. This concern about losing control did not arise in the Aboriginal group or in the Chinese Catholic group.

Caucasian men more often noted their limitations and challenges as external forces that impeded their ability to provide good care, such as a failing healthcare system. The Chinese Catholic and Aboriginal groups more often described their limitations and challenges as internal instead, such as learning patience, or feeling too caught up in their loved one's needs.

Finally, many Caucasian men noted a strong personal transformation brought on by the challenges of caregiving, something not raised by the Aboriginal or Chinese Catholic group. Aboriginal men described their caregiving as affirming their identity within their community, and the Chinese Catholic men described meeting the social expectation of providing care for their loved ones. We suspect this difference also has a cultural component, as Caucasian men described stepping outside of their community's gender expectations to provide care. This stepping outside of social expectations can provide

an opportunity for such a transformation, which many considered the most important impact their caregiving work had on them.

There were no differences between the groups in the ways men found to help themselves cope with caregiving. Most often they reminded themselves of their purpose, and the love they have for the person they cared for. Many reported feeling a sense of pride, satisfaction and accomplishment, even gratitude for their ability to help their loved one in such an intimate journey. Those feelings helped them understand their work was important and needed and meaningful.

Every group reported a fair amount of self-talk to keep them focused on the work they had undertaken. Every group apart from the Aboriginal group relied on cultural messages related to gender, cultural touchstones about men's work and men's roles in the world and their community. The Aboriginal group expressed these cultural touchstones in terms of being human, and the human community.

While men do provide emotional support to their loved ones and rely on friends and family for their own emotional support, several noted how difficult it was for them to admit this, feeling uncomfortable around emotional issues. While a few utilized counsellors, no one suggested they would have liked more counselling. Instead, many noted a need for greater visibility and appreciation for their efforts in the larger community, to find male role models and ideals they could learn from.

The men in this study reported some negative impacts of caregiving, but the strongest emphasis by far was on caregiving's positive aspects, which generally coalesced into four major themes: A strengthened emotional connection with the person they cared for; a deep satisfaction with their ability to help; an increased spiritual or philosophical outlook on life; and for Caucasian men in particular, a sense of personal transformation.

Across all groups men described feeling proud, honored, and deeply satisfied with their ability to help their loved one. They felt a sense of satisfaction that their loved one was being helped, and a humble kind of pleasure that they could do such good. Many felt they received a new perspective on life and

death, were able to think about death in a new way, as an important aspect of life. They came to a better understanding of their human limits and learned how to accept painful realities.

RECOMMENDATIONS

This project came up with a number of recommendations that we would like to highlight:

Rethinking the definition of caregiver

As a result of this project we now question whether the current societal/cultural definition of “caregiving” may be the barrier that inadvertently excludes men from being considered (or considering themselves) as “caregivers.” Hospice Toronto will use this information to clarify and expand the definition of caregiver inclusive of cultural and gender-specific strengths.

Challenging assumptions around gender choices in caregiving

This project focused on the needs and experiences of male caregivers. This project did not gather information from people who have concerns or questions which may create barriers to having male’s supporting them in a caregiving capacity. We decided to leave those questions for future studies.

Expressed continued need for education and support

Hospice Toronto will develop resources and education that is inclusive and to further enhance Caregiver resources that focus on Seniors and Male Caregivers. This will be used as an education/resource/information tool kit for clients and caregivers and that will emphasize the tools discussed by this project’s respondents. Information/education could include: practical caregiving tasks, disease progression, respite and in-home care resources in the community, advocacy support, family dynamics, coping strategies (getting through the work), emotional support and navigation of the health care system.

Utilization of men caregivers as role models/mentors

Hospice Toronto will explore ways in which we can encourage male caregivers to become role models for other men in their communities. This will include finding greater visibility and recognition for the caregiving already being provided by men.

Communication

Hospice Toronto will disseminate our findings to hospice staff and study participants and other community agencies who want to better understand the challenges and rewards of being a male caregiver.

Reframing the role of men as caregivers

This study explored caregiving from the male perspective and found many men can and do step forward to provide quality care for their loved ones. Once men take on the role of caregiver, how they provide that care relies on cultural touchstones of male identity that are both effective and supportive, and provide as many benefits as they present challenges.

Hospice Toronto program enhancement

The data from this study has provide Hospice Toronto with information on how to develop best practices to support men who assume a caregiver role in their families, and new ways to recruit, train, and support male hospice volunteers.

Acknowledgements and Thanks

We would sincerely like to thank our participants (individuals, agencies and partners) for not only giving of their time and their stories for this project but for making a difference in their loves ones life by being their caregiver. We end by including the words of wisdom respondents shared with us. This report is dedicated to each one of you.

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Appendix A: Words of Inspiration and Wisdom:

The following are all complete quotes of their written comments

- It feels good to be a help and positive force to someone who can't help themselves
- You have to force time to yourself and find something to laugh about. I named her legs one night when they annoyed me so that I could swear at them and not her. It sure helps to be creative...
- Be knowledgeable as possible.
- Don't be afraid to make demands. There is no effective oversight of the CCAC, so it is often unresponsive, but some of the CCAC personnel are caring and dedicated, and really do want to help; but you must let them know in no uncertain terms that you need help.
- Get to a support group, learn the skills to survive being a caregiver, live for the day, learn to accept and manage.
- It can make you a better person.
- Company and conversation help stimulate and pass time.
- It's important to be there for our aging relatives.
- Not sure this is relevant. I was a son helping his parents.
- Find the joy in the job.
- Can be an honor to be present with someone at that time.
- Acceptance. Go to the "bitter end" and then go beyond.
- The experience, although challenging, was worth the emotional pain.
- Be present for the person and focus on what their needs are.
- It's all impermanent and changing, so when the going gets rough, know that there will be an end.
- People can only change when they are ready and accept the situation.
- We are all in this for the duration.
- "Don't waste your mother's death."
- Enjoy every day as if it's your last day
- "The strongest steel is tempered in the hottest fire."
- Important to take the care when it's offered and be sure to take necessary time for your own health.
- Keep a balance between self-care and care of others.
- Be cautious of personal involvement but care.
- Take time for yourself.
- Don't be afraid to ask questions; don't be afraid to ask for help.
- Keep up the good work.

- Here is your pat on the back!
- Patience, understanding.
- Never, ever give up.
- Don't be afraid to be honest about how scared you are.
- GOD
- Be strong. There will be moments of joy that will make the sacrifice worth while.
- Tell the individual, as often as possible, that you love them
- It's tough work and it wasn't until the very end, when it got extremely difficult, that I realized how some caregivers have a much more demanding task than I ever did. Do what you can and do not hesitate to seek out help. Also, be aware of your own thoughts and try to understand the cause and how to deal with resentment. It is a very real issue and can be helped with communication with the person you are caring for.
- It will be tough. But when you are able to go home and sleep at night, you know you did the right thing.
- Make a difference in the life of a loved one - whether or not they are able to thank you, your assistance is truly appreciated and you will never have regrets after they have passed on.
- Stay focused on the task at hand. The time that you get to spend with the individual is a gift and one that should always be treasured. This person is giving you a gift which cannot have a value associated with it - the gift of their time.
- Being an active, involved caregiver to an intimate friend who is dying can be one of the most satisfying and constructive ways of coping with and preparing for the ultimate loss of your partner. Now, seven months after her death, I have no regrets and many cherished memories of countless tender moments we shared together over the final three years of her life. This is what life is about, and (except for the missed opportunity to grow old together, of course), it really doesn't get any better than this.
- You must always make sure that if you are in a position to care for someone, that you do not forget yourself or other family members. If you do not take the time, you will burn out quickly. Never be shy in asking for help. Should you have to attend doctor's appointments, hospital clinics or hospital stays be prepared. Have your questions written down. No question is too silly to ask. Do research and try to join a support group. Keep well informed of programs, funding, etc. Do not be afraid to speak out.
- If you have it in you to care for someone that you love or who needs you in the moment and you are capable of providing some care then do it. You will never forget it. It will make you see life

differently and you will gather strength from the experience.

- I found that I was very busy with work and chores; I regret not taking more time out to realize how sick someone can become. I feel I could have done more and been there more had I realized this. I still regret not fully understanding the limitations and finality of death.
- Get your emotional needs outside of agency do it because you like it. Advocate for higher wages.
- Take a breath and "note the changes"...every moment is blessed.
- You can do more and handle more then you believe you can. Do not be afraid to talk about your feelings and you must ask for and receive help from what resources you have.
- Feel the fear, and do it anyway!

Additional Comments from Online Respondents

- Would I do it again.... I don't really know... But I'm here now...
- Continue being part of the caregiving team.
- What would be useful, for all disabled people, is a push for more public rest rooms that a caregiver and his/her charge of the opposite sex could use. This really ought to be made more of an issue as regards access.
- Be appreciative to those who do help.
- "Surgite! Push on!"
- I know that decision that our family made to keep our son at home was our decision. Other people may not be able to do what we did and that they cannot be judged. You can try to help and share your wisdom but you have to watch because not every case is the same and many people do not like to have advice given to them. You have to be very careful. Trust in yourselves and the satisfaction is huge.
- I would do what I did a million times again if it would help just one more person one more day.
- My mother had a fairly easy exit into heaven. Her peace came early in the morning, a routine for her to get up and start the day. Her beautiful foot was reaching for her slipper- almost made it and then, stilled. I can only hope that others will know that helping a loved one is so very important, to a stranger, relative or loved one...it's about the biggest thing you can do- is care for someone.
- These experiences helped me care for my father, and other close friends as they were dying. I was very grateful for that comfort level.
- It was a pleasure to express myself in this way.
- It was a pleasure being able to share my experiences with others. I hope that it helps.
- Thanks for doing this research.

Appendix B: Making a Difference: Exploring the Experiences & Needs of Male Caregivers

Focus Group Questions

We would like to ask you the following questions based on your caregiving experience:

Why did you become the person's caregiver?

As a caregiver, what did you have to do?

Was there anything you were asked to do as a caregiver that you were uncomfortable doing?

Where there any limitations/challenges?

What helped you get through it?

What impact did being a caretaker have on you?

What were some of the positive aspects of caretaking?

Bibliography

- Becker, G *Disrupted Lives: How people create meaning in a chaotic world* (Berkeley, CA: University of California Press 1997).
- Brazil, K., Thabane, L., Foster, G., Bedard, M. “Gender Differences Among Canadian Spousal Caregivers at the End of Life,” *Health and Social Care in the Community* 17 (2009): 159-166.
- Burton, L.C., Adaniuk, B., Schulz, R., Jackson, S., & Hirsch, C., “Transitions in Spousal Caregiving,” *The Gerontologist* 43(1997): 230 – 241.
- Braithwaite, V., “Understanding Stress in Informal Caregiving: Is Burden a Problem of the Individual or Society?” *Research on Aging* 18 (1996): 139-74.
- Calasanti, T., King, N., “Taking Women’s Work Like a mMan: Husbands’ Experience of Care Work,” *Gerontologist* 4 (2007): 516. Retrieved from <http://elibrary.bigchalk.com>
- Cohen, M., Katz, D., and Baruch, Y, “Stress Among the Family Caregivers of Liver Transplant Recipients.” *Progress in Transplantation* 17 (2007): 48-53
- Harris, P.B., The misunderstood caregiver? A qualitative study of the male caregiver of Alzheimer’s disease victims. *The Gerontologist*, 33 (2007): 551 – 556.
- Kramer, B.J., “Men Caregivers: An Overview,” *Men as Caregivers: Theory, Research, and Service Implications*, eds, B. Kramer and E. Thompson, (New York: Springer Publishing, 2007) 3-19.
- MacRae, H., “Managing Feeling: Caregiving as Emotional Work,” *Research on Aging* 20 (1998):137-60.
- Mathew, L.J., Mattocks, K., Slatt, L.M., “Exploring the Roles of Men Caring for Demented Relatives, *Journal of Gerontological Nursing* 16 (1990) 20 – 25.
- Micka, K., *Men as Caregivers: Beyond Toughing It Out*, 2006. Retrieved March 8, 2007, from <http://www.deloro.org/article06.htm>.
- Perkinson, M.A., “Socialization to the Family Caregiving Role Within a Continuing Care Retirement Community,” *Medical Anthropology* 16 (1995): 249-67.

Russell, R., In *Sickness and in Health: A Qualitative Study of Elderly Men Who Care for Wives*

With Dementia, *Journal of Aging Studies*, 15 (2001) 351-367.

Wallsten, S.S., "Effects of Caregiving, Gender, and Race on the Health, Mutuality, and Social Supports of Older Couples." *Journal of Aging and Health* 12 (2001): 90-111.