

THE OFFICIAL
MAGAZINE
OF THE CENTRE
FOR STUDIES ON
HUMAN STRESS

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The Stress of Caregivers

Robert-Paul Juster
& Marie-France Marin

Whenever we put together an issue of *Mammoth Magazine*, we try hard to find a current topic related to stress that our readers can relate to. After all, our main goal is to provide you with scientifically valid information on the stress of our lives. In light of this, we hope to provide you with knowledge and practical advice to better manage your daily stress. For our 10th issue of *Mammoth Magazine*, we continue along this journey, and have decided to go one step beyond our normal path by giving homage to those faced with a stressful reality; namely, to be a caregiver for a loved one afflicted with physical and/or psychological illness.

According to Statistics Canada, about 2 million Canadians are caregivers. Quite evidently, they are an invaluable national resource that benefit those they care for and society at large. In

effect, by providing care and support, caregivers save our nation astronomical health costs. Unfortunately, this noble act of altruism can also come with a heavy price to the caregiver. That is because being a caregiver in an inherently stressful circumstance.

When faced with illness, it is quite natural to feel diminished control. What's more, we cannot control the reaction of loved ones when we are given a diagnostic, many of which are unpredictable, as are disease progressions and responses to treatment(s). Most caregivers are not initially prepared to handle this new situation, new disease and the new relationship dynamic that develops with those dependent on their care. Finally, the caregiver must henceforth accept a role that was not necessarily one they were planning on embodying and must often learn to juggle multiple roles at different times. In all of these situations, the recipe for stress is present as the NUTS stress recipe (Novelty, Unpredictability, Threat to the Ego, and diminished Sense of Control).

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The Stress of Caregivers

As you will see throughout this issue, the scientific literature on caregiving is not a joyful affair and is often viewed as a human model of chronic stress. You undoubtedly know that chronic stress can contribute to the development or exacerbation of certain physical and psychological problems. However, we must look beyond this and rather reflect upon the two sides of the coin. Consider first that most caregivers consider their experience to be gratifying and find solace in feeling useful and beneficial to their loved one. Moreover, we must never forget the importance they have in the lives of their cared upon and the very real differences they make in their well-being.

For this 10th issue of *Mammoth Magazine*, Nathalie Wan, research coordinator at the Centre for Studies on Human Stress, begins with a very interesting article on the existing scientific literature on stress in caregivers. She also gives tribute to caregivers that tend to persons suffering from mental health problems. To this day, there still exists a lot of stigma attached to mental disorders in our society. Imagine the harsh reality of having to deal with not only the responsibilities of caregiving, but also to be confronted with the stigma associated with mental disorders.

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In our second article, Marie-France Marin, Doctoral student at the Centre for Studies on Human Stress, addresses the work of Dr. Nicole Ricard. Dr. Ricard is a researcher and professor emeritus at the Faculty of Nursing Sciences of University of Montreal. She is a pioneer in this research domain in Quebec and has devoted her career to compassionately understanding the reality of caregivers. More precisely, she wanted to pinpoint the exact health consequences experienced by caregivers by identifying the precise factors that burden them.



Next, Shireen Sindi, Doctoral student at the Centre for Studies on Human Stress, signs the third article of this issue. Ms. Sindi interviewed two women who are caregivers to their husbands who suffer from Alzheimer's disease. As part of her interview, Ms. Sindi also had the chance to speak with a representative of the Alzheimer Society of Montreal. Throughout her article, she clearly exposes the experiences of all involved. As part of their testimonials, these two caregivers also generously provide us with advice to better face the realities of caregiving.

To all the caregivers who read this, to their near and dear, and finally to those who are touched by the care of caregivers...we would like to dedicate this 10th Mammoth Magazine to you all.

Likewise, Julie-Katia Morin-Major, research assistant at the Centre for Studies on Human Stress, interviewed the family of a youngster afflicted by schizophrenia. Ms. Morin-Major witnessed a touching familial testimony that has so kindly been shared with all of us. You will also see to what extent these moving stories help us better understand the nuances in the experiences of caregiving.

Finally, Nathalie Wan and Dr. Sonia Lupien co-author the final article of our 10th issue of *Mammoth Magazine*. Being first and foremost scientists with a thirst to learn, we are also invested in helping the populations we study. That is why the Centre for Studies on Human Stress has decided to conduct a study of caregiver stress. Mrs. Wan and Dr. Lupien explain the motivations behind this study and the principal objectives. If you are interested in participating in this study, you will also find all the necessary information to do so in this co-authored article.

We hope that these articles will allow you to learn more about the realities of caregiving and appreciate the extent to which we are all in some way affected...after all, no one is completely protected from illness.

To all the caregivers who read this, to their near and dear, and finally to those who are touched by the care of caregivers...we would like to dedicate this 10th *Mammoth Magazine* to you all. We hope you will take a certain level of comfort and can put to good use some tips and experiences shared in order to help you better cope with your stress. 🐘



If you are a caregiver or you know one, here are some useful resources.

ENGLISH RESOURCES

- **Care-ring Voice Network**
www.careringvoice.com/
- **Caregiver Connect**
www.caregiver-connect.ca/en-us/Pages/Home.aspx
- **Canadian Caregiver Coalition**
www.ccc-ccan.ca/index.php
- **The Family Caregiver**
www.thefamilycaregiver.com/
- **Alzheimer Society of Montreal**
www.alzheimermontreal.ca/index_en.php

FRENCH RESOURCES

- **Regroupement des aidants et aidantes naturels de Montréal**
www.raanm.org - 514 374-1056
- **Institut universitaire de gériatrie de Montréal**
www.aidant.ca/_home
- **Réseau entre-aidants**
www.reseauentraidants.com/
- **Aidant en réseaux**
www.caregiver-connect.ca/fr-fr/pages/home.aspx
- **Canadian Caregiver coalition**
www.ccc-ccan.ca/index.php
- **Société Alzheimer de Montréal**
www.alzheimermontreal.ca/

The Stress and Stigma of Caregiving

Nathalie Wan

Stress associated with caring for an elderly person or a physically or mentally ill person can compromise caregivers' health at multiple levels. Physical, psychological and social strains are all consequences of the long-term experience of caregiving. Although some caregivers are able to cope well with their difficult role while experiencing few symptoms of distress (some even have positive gains from the experience), growing bodies of literature document the stressful nature and health risks of being a caregiver.

Caregiving maintains all the features of a chronic stressor.

Caregiving maintains all the features of a chronic stressor. It involves psychological and physical strain over long periods of time, has the capacity to spillover into various areas of life such as the workplace and family relations, and it is frequently accompanied by high levels of unpredictability and often requires demanding vigilance. Caring for a family member with a physical or mental health problem is a significant chronic stressor in humans. In fact, caregiver stress is currently seen as a human model of chronic stress in the stress literature.

To inform you on this area of research, this section reviews the negative health outcomes of caregiving and studies that have examined the psychological, physical, physiological and social consequences of caregiving.

Psychological outcomes

More than 40 years of research in the field of stress has now provided us with the mechanism by which chronic stress in humans can lead to cognitive and mental problems. Studies on caregiver stress have revealed that caregiving can bear negative effects on the psychological health of the caregiver. Due to the stressful nature of providing care for an ill family member, caregivers demonstrate high levels of psychological distress and are shown to have higher levels of depressive symptoms, clinical depression, and anxiety than the general population or non-caregivers.

In addition to psychological effects, diminished cognitive function and general emotional distress also result from caring for a relative with a mental illness. In one of the few studies on care-

giver stress and cognitive function like memory and attention, women who provided care to their ill spouses were found to have poorer cognitive functioning on several cognitive tests.

It has also been shown that family members of patients with schizophrenia experience increased shame proneness and greater distress. The results from this study by Lee and colleagues in 2004 also suggest that caregivers of patients with schizophrenia who are shame prone may be disposed to view incidents, such as having a relative with a mental illness, as something that reflects negatively upon themselves ("I am a bad relative" or "I have faulty genes"). This implies that it is of great importance to evaluate caregivers' shame proneness as this could help identify family members who may be at particular high risk for experiencing depression, anxiety and stress.

Recently, researchers and practitioners have focused not only on providing care as a source of distress, but also on the caregiver's perception of how much the patient is suffering. Patient suffering is evident in three ways: (1) overt physical signs, including verbal and nonverbal expression of pain and physical discomfort, such as difficulty breathing; (2) psychological symptoms of distress, such as depression and apathy; and (3) existential or spiritual well-being, reflecting the extent to which religious or philosophical beliefs provide inner harmony, comfort and strength, or alternately, lead to despair. Specifically, it has been shown that two types of patient suffering – emotional and existential distress – are significantly associated with caregiver depression and use of antidepressant medication. This demonstrates that the intensity of caregiving may contribute to diminish caregiver health.

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Physiological outcomes

Caregiver stress has been linked to adverse physiological health in a large number of studies. Physiological outcomes include elevated blood pressure, heightened cardiovascular reactivity, risk for coronary heart disease, elevated stress hormone levels, lower immune functioning, and even increased mortality among spousal caregivers.

A number of studies have examined the effects of chronic stress on cortisol, an important



stress hormone. In particular, one study reported elevated cortisol levels in older caregivers of patients with Alzheimer's disease. Similar effects have been observed in a study of younger caregiving wives of patients with physical problems whereby there was a difference in caregiver and noncaregiver cortisol.

Further physiological effects of caregiving are apparent in a more recent study on the impact of caregiving strain and the risk for stroke and coronary heart disease among spousal caregivers. The study showed that high caregiving strain was found to be associated with higher estimated stroke risk with greatest effects for men, particularly African American men, providing care to their wives. Another study reported an almost twofold increase in risk for coronary heart disease in women who provide care to a disabled or ill spouse for 9 or more hours per week. According to an earlier study by Lee and collaborators from 2003, regardless of the caregivers' sex, the stress of providing care can be, in itself, a risk factor for stroke and coronary heart disease. It is suggested that highly strained caregivers can benefit from effective caregiving support and intervention.

Clearly, the immense stress and strain of caregiving impinges on caregivers' physiological functioning and increases their risk for physical health problems, even leading to increased mortality. Ultimately, caregivers are at greater risk of mortality than noncaregivers. In an edifying study, caregiving has been identified as an independent risk factor for death with increased risk of mortality in individuals experiencing caregiver strain over a 4-year period. Collectively, these studies demonstrate that caregivers are at risk for serious negative health outcomes.

The Stress and Stigma of Caregiving

Physical outcomes

The chronic stress of caregiving affects numerous dimensions of caregiving health, including self-reported health, health symptoms, illness and medication use. A revealing study has shown that caregivers experience a one-third increase in negative health symptoms after assuming caregiving responsibilities. Spousal caregivers also report an increase in days ill due to infectious disease than noncaregivers. Caregivers who report higher levels of caregiving stress have poorer self-rated health, poorer physical function, more symptoms and high levels of depressed mood. Unsurprisingly, caregivers use significantly more prescription medication than noncaregivers.

Self-care is often compromised as caregivers provide a high level of care. Common complaints include forgetting to take medications, having no time to exercise, see a doctor or rest when ill, and insomnia. Several studies report sleep problems as an adverse physical outcome of caregiving. In a similar vein, caregivers whose sleep was frequently disrupted were about 2.5 times more likely to suffer from poor mental health, compared to those caregivers whose sleep was not disrupted.

Social stigma

In 2001, the World Health Organization declared stigma and discrimination associated with mental disorder to be the single most important barrier to overcome in the community. Stigma affects people with mental illnesses, as well as their families. In addition to chronic stress and its' physical, psychological and physiological impacts on caregivers, some caregivers endure the social stigma of providing care to a person with a mental illness.

In a study of 162 relatives (spouses, children or siblings) of mentally ill patients conducted by Link and coauthors in 2001, 10% of respondents felt the burden of the situation of being a relative so heavy that they thought of suicide. Moreover, the stigma experienced by caregivers of mentally ill patients caused caregivers to retreat from their social support role and adopt avoidant coping mechanisms in order to fend off anticipated social rejection.

Studies have shown that about 70% of caregivers of people with mental illness report feeling stigmatized, and that perceived stigma is associated with reports of depressive symptoms.



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In a nation-wide survey, 50% would tell friends or coworkers that they have a family member with a mental illness, compared to 72% for a diagnosis with cancer. An illuminating and revealing study in the U.S. asked employers about job-offer intentions, and results showed that ex-convicts were seen to be more acceptable than people with mental illness. Alarming, the only group less favored by employers were those with tuberculosis.

For a caregiver of a mentally ill person, the chronic stress of caregiving is coupled to the constant threat of being stigmatized and discriminated against. Studies have shown that individuals who report having faced discrimination are more likely to experience poor physical health.

Conclusion

The literature on caregivers clearly indicates that the intensity of chronic caregiving is associated with a multitude of health issues. From the psychological strains of providing care, to the physical toll and social stigma identified with caring for a mentally ill relative, the caregiving experience places a cumulative toll on the body. With significant burden and stress load being associated with poor health outcomes, viewing the various perspectives of caregiver stress may help us to better understand and implement clinical strategies to reduce or prevent the debilitating physical, psychological, and sociological effects of caregiving. Most importantly, society as a whole must get involved in helping caregivers by applying empathy and compassion. 🐾

The Gift of Caregiving

The selfless sacrifices made by caregivers are a priceless gift to those in need and exemplify the most noble human virtues of loyalty, respect, and compassion. The gift given by caregivers is often unreciprocated and even dangerously overseen by others, let it be fellow family members who are frightened to get more involved or by discriminatory beliefs of society that also limit further involvement. This must change. What separates humans from other animals is our ability to care for the sickly, and we must always keep in mind how we would like to be treated should misfortune befall us.

Be mindful and sensitive to caregivers and offer them the social support that soothes their predicament and helps them cope. In particular, be observant of subtle changes in their moods (e.g., irritability, hopelessness, forgetfulness), physical signs (e.g., fatigue due to insomnia, reduced mobility, weight changes), and health behaviors (e.g., cleanliness, dietary changes) that might signal distress of an increasingly overwhelmed caregiver. Because humans do not always ask for help, we can do our part by offering it regardless.

Researcher's Profile: **Dr. Nicole Ricard**

A career devoted to caregivers and to people suffering from mental disorders

Marie-France Marin
Translation: Robert-Paul Juster

Dr. Nicole Ricard is professor emeritus in the Faculty of Nursing Sciences at University of Montreal. She started as a practicing nurse primarily in the domains of mental health and forensic psychiatry, while also teaching nursing sciences before undertaking a Doctorate in Counseling. From the get-go of her career in research, it became clear that she would one day develop a program oriented towards the experience of caregiving. But why would anyone be interested in this unpopular subject that was, compared to today, much less known by the general population? At the time, Dr. Ricard was herself a caregiver of a loved one afflicted with mental illness. Throughout this experience, she quickly realized that it wasn't easy to navigate through the health care system in order to obtain the necessary information to benefit the well-being of the person afflicted. Likewise, it was not easy to assume the role of a caregiver. So, if it was difficult for her, who was knowledgeable of health – being, after all, a nurse - just imagine how it would be for people who had no contacts and little knowledge on the subject. One question emerged in Dr. Ricard's mind and it was this that made her decide to devote her career to how caregivers and those close to individuals afflicted with mental disorders possibly go through this demanding experience.

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When Dr. Ricard was starting her research career in 1989, the government implemented the first political mandate on mental health in Quebec supporting the notion that it was essential to consider family members as vital partners in supporting loved ones in their care. While nice in theory, the reality of the situation was quite different. In effect, during this period, the family was seen as the principle body responsible for the diagnosis of a mental disorder. Note that also at the time, the scientific literature put into question the responsibility of families in the etiology of mental disorders

and precipitously underlined the important contributions of certain genetic and environmental factors at hand. This pervasive and persistent attitude held by the health system essentially pointed blaming fingers at families for mental misfortune. Such shameful attitudes rendered the task that much more difficult for caregivers and obstructed the path towards actually being viewed as partners in the treatment and rehabilitation of their loved ones. Dr. Ricard was therefore convinced that it was necessary to understand the experience of caregivers at multiple levels: their situation, the support they themselves received, and the effects that caregiving had on their own lives. What exactly were the obstacles faced by families and inherent in the caregiver role? Could there be repercussions on the health of caregivers?

The first major study by Dr. Ricard revealed that only 12% of caregivers lived no encumbrances that were objective (ex: work absence) nor subjective (ex: reported fatigue, feeling overwhelmed) in nature. This suggested that the vast majority of caregivers were confronted by some level of distress. Indeed, this first study demonstrated that psychological distress as well as problems related to sleep were significantly higher in caregivers compared to the general population. As an example, it is estimated that 20% of the general population have elevated levels of psychological distress, where as this statistic sky rockets to between 20% and 58% for caregivers.

Another interesting piece of the puzzle coming out of this research was the fact that the situation for caregivers could be visualized everyway but linear. In effect, some situations were better than others, which essentially renders the experience more variable and cyclic. It seems like the weight on the shoulders and psychological distress felt by caregivers is directly related to the actual conditions manifested by the cared for. In other words, as the patient's situation deteriorates or during periods of crisis sometimes necessitating hospitalization, the load on the caregiver becomes heavier. As seen in our last issue of Mammoth Magazine, it seems that having low socio-economic status is associated to ever higher levels of distress. If we add this circumstance to the stress and strain of being a caregiver, we come one step closer to better understanding the results obtained by Dr. Ricard and her team.



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One of Dr. Ricard's studies also revealed that during a crisis, 42% of caregivers did not ask for help. The plain fact of not asking for help can come at a hefty price. To this effect, Dr. Ricard finds evidence suggesting that caregivers that were under the impression that their loved one's state was not improving and who did not have access to exterior help, experienced a greater burden that was also related to long-term physical health problems. This therefore underlines the importance of seeking help and support.

How to swim forward without losing one's scales?

As has been clearly highlighted in the previous article, the experience of being a caregiver can be incredibly challenging and stressful. It is for this reason that we must build tools and develop strong coping strategies to facilitate adaptation in the aims of traversing successfully through this experience.

As you might recall, stress is an individual experience where what is stressful for one person is not necessarily stressful for another. This means that there is no one universal way to cope with stress nor how to adapt to different situations. It is essential to learn to identify the best strategies for the person. The caregiving experience is no exception to this rule. It is without a doubt a stressful experience and the best way of negotiating issues day by day really depends on the individual living it. First and foremost, it is important to pin-point the

Researcher's Profile: Dr. Nicole Ricard

stressful ingredients of the situation (www.humanstress.ca/stress/understand-your-stress/sources-of-stress.html) and to work through each of these in turn (www.humanstress.ca/stress/trick-your-stress/principles-of-stress-management.html).

When we asked Dr. Ricard what she thought were the best tips and tricks to effectively conserve a certain level of balance in life as a caregiver, she maintains that the golden rule is to keep a sane level of emotional distance from the person afflicted with the illness. Quite understandably, this is much easier said than done. But with time, we become ever more adept at knowing who we are as a person and as a caregiver, and in so doing we become ever more understanding of the personality of the afflicted person and the evolution of the illness. One must arrive at a level of understanding that one can help, but that we are not responsible for the behaviors of our loved ones. It is so important to avoid falling into thoughts that place blame on oneself. By investing oneself in this manner, and in keeping a certain distance, yet closeness, we can become better able to manage the situation in its' different forms of avoiding any personal blame. It is equally essential to surround yourself with people for whom you can count on to be there when needed.

Granted that the caregiving experience can be an extremely gratifying one, we must be able to delegate certain responsibilities and to accept help when it is offered. Dr. Ricard also mentioned that help groups can be extremely beneficial. In fact, there are several such groups for caregivers.

Having the chance to exchange stories with others, these help groups offer the opportunity to partake in conferences and workshops on diverse topics in order to equip the caregiver with the necessary tools to utilize on a daily basis.

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We can affirm that Dr. Ricard is a pioneer in this research and for the plight of caregivers assisting individuals suffering from mental disorders. It is time for society now more than ever to join the scientific community in applauding, acknowledging and appreciating the exceptional contributions of our caregivers. Physical health problems are much better understood by the public and socially accepted; it is time for mental health conditions to receive the same level of understanding even if it is difficult to do so.

By increasing our knowledge on this subject, we will consequently diminish the associated stigma, and in doing so, we will all contribute to improved quality of life for the person who is ill as well as that of their close ones who far too often must endure the judgments and incomprehension of others surrounding them. 🐘



New Web Site

We are pleased to announce that the new Centre for Studies on Human Stress website is up and running.

We invite you to come and surf our improved site.

Among other things, you will find:

- a whole array of information on stress
- information for specific populations (the stress of parents, of youths, of elders, of workers, etc.)
- all issues of our *Mammoth Magazine* (freely downloadable)
- a FAQ section with videos where experts respond to your questions regarding stress and mental health
- tools for researchers (upcoming conferences and technical information on stress) information concerning our different educational programs

Come visit us!
www.humanstress.ca



In Their Own Voice:

Caregivers Share Their Experiences

Shireen Sindi

Caregiving for a loved one with Alzheimer's disease (AD) can be very demanding. In order to understand the stress and strain involved, the Centre for Studies on Human Stress is extremely interested in learning and listening to caregivers' experiences. Thanks to the Alzheimer Society of Montreal (ASM), we were allowed to interview two caregivers – Jacqueline and Odette – attending to their husbands. We were also privileged to speak with the Director of Programs and Services at the ASM, Ms. April Hayward.

Caregivers face many challenges and responsibilities that change depending on the disease stage. When asked about the greatest challenges faced, all caregivers mentioned the immense energy required, which often includes living at another person's rhythm. Odette said "On a daily basis we need to learn how to offer care. After all we're not necessarily trained to become caregivers. It is a novel experience". Jacqueline mentioned that it was difficult to accept the change of roles, "I had to accept no longer having the husband I once had. I became his mother instead of his wife". According to Ms. Hayward, "with AD, there is an important emotional impact. Seeing someone you love change as the disease progresses is painful and can trigger complex grieving responses".

Despite the challenges involved, caregivers are empowered by seeking helpful coping strategies.

Despite the challenges involved, caregivers are empowered by seeking helpful coping strategies. The importance of being informed and learning about the disease and available resources (such as the ASM workshops) seems to be of paramount importance, as these services offer an increased sense of control. "The more knowledgeable we are, the better we are at caregiving", says Odette. Caregivers also expressed how essential it is to take care of oneself by getting good sleep, eating well, and maintaining relationships with family members and friends. Another important factor is regular attendance of support groups and sharing one's experiences with a social network. "Listening to stories told by others reminds us that we're not alone, and sometimes shows us that others are worse off", said Odette.

AD patients also benefit tremendously from the camaraderie of such community centres. "When my husband goes to the ASM day centre, this offers me respite and it's also great for him, as he socializes with others & is involved in cognitive and physical stimulation activities. When he gets back home, I find him in a better mood and with a better appetite than usual". These strategies may be helpful for most caregivers, although we must recognize that different ways of coping are an individual's choice and can depend on the circumstances.

Caregivers need a great deal of support in different forms, let it be practical or emotional support. Unfortunately, most caregivers report that they do not receive sufficient support. "We need to educate our social network on how to help us. Friends and family members do not necessarily understand why the situation is stressful and how they can help," said Jacqueline. Likewise, Odette said, "I wouldn't say that I'm getting much support. My children visit occasionally, but I also understand that they have their own demanding lives and responsibilities. We can only have reasonable expectations".

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In Their Own Voice

Caregivers Share Their Experience

When Ms. Hayward was asked about the support that caregivers receive, she responded that: “caregivers frequently express feeling disappointed with the resources that have been offered to them, and describe this as one of the biggest challenges and frustrations that they face. Organizations like ours seek to respond to existing gaps, and advocate for resource creation”. AD and other dementias are on the rise as populations worldwide are increasingly older. This clearly calls for a great need in providing more resources to help at all levels of society. We need to open and strengthen communication among caregivers, their family members, and the social networks that foster communication and invaluable help.

In recent, years, we’ve seen some progress in decreased social stigma associated with AD. Society is slowly listening and people are increasingly knowledgeable and aware of realities and myths. Indeed, individuals with AD can be involved in meaningful and engaging activities at many stages of the disease. But stereotypes like those saying that AD patients are aggressive and dangerous have serious implications: caregivers can become isolated when family members feel uncomfortable around the individual with AD. “We don’t feel stigmatized, but rather we feel that the disease is misunderstood,” said Odette. “The more people challenge the stigma associated with AD, the less fear there will be for those newly diagnosed and their caregivers” says Ms. Hayward.

Our interviewed caregivers want to share a few important messages to new caregivers. Let in-

“The more people challenge the stigma associated with AD, the less fear there will be for those newly diagnosed and their caregivers” says Ms. Hayward.

dividuals with AD engage themselves in as many diverse activities as their condition permits, share your experiences with other caregivers, family members, and your social networks at large, and be sure to maintain existing relationships. Odette further expressed the importance of living one day at a time: “We do not know what will happen, and it is all unpredictable. One should therefore be informed, be as prepared as possible and accept the situation”. It is also important to be realistic: “It’s normal to have difficulties adapting, and one should not feel guilty about not having enough patience. We’re not saints. Instead one should understand it as a sign of needing to seek help”, suggested Jacqueline.

As Rosalynn Cater once said, there are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who need caregivers.”

“Caregiving touches each of us in many varied ways during our lifetimes” expressed Ms. Hayward. As the number of caregivers rises, society as a whole must learn how to offer caregivers better support and enable them to detect signs of chronic stress. As Rosalynn Cater once said, there are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who need caregivers.”

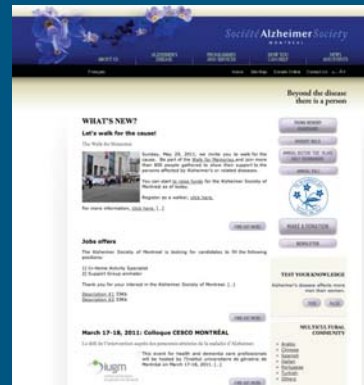
We would like to acknowledge our deepest gratitude and utter respect to the Alzheimer Society of Montreal, Ms. April Hayward, and the caregivers interviewed for generously offering their time and sharing their experiences with us.



Société Alzheimer Society
MONTREAL

SINCE 1981, the Alzheimer Society of Montréal works to alleviate the social and personal consequences of Alzheimer’s and related disorders, as well as to promote research into their causes and cure.

Programs and services such as the availability of specialized counselors, support groups for people diagnosed and their family/informal caregivers, respite and stimulation services as well as therapeutic approaches like art therapy have been developed at the ASM to offer support and education to families. In addition, trainings and conferences are offered to health professionals in order to promote quality care for people with Alzheimer’s disease or a related disorder. Lastly, awareness activities such as public lectures are organized to sensitize the public to issues surrounding this disease.



www.alzheimermontreal.ca

Kin's Family

Julie-Katia Morin-Major
Translation: Robert-Paul Juster

Taking care of a person who is ill is never easy, especially when the person is a loved one. What's more, when this person suffers from a mental disorder, we must often also deal with stigmatization surrounding the disorder. For this article, I met a family doing everything in their power to help their son Kin who is afflicted with schizophrenia. In the following passages, I will share with you the warmth and dedication that I felt when meeting this inspiring family.

Upon noticing the first signs of behavioral changes around the age of 16, Kin's parents, Catherine and Joaquin immediately started asking themselves questions. Kin, who was an excellent student, had a significant drop in his scholastic grades. Also, being a naturally social person, he began not wanting to really engage in activities with friends and family. As Kin was the eldest of the family, it was difficult for Catherine and Joaquin to know whether his behavioral changes were abnormal or simply manifestations of adolescence. This being said, certain behaviors were more revealing than others and sounded bells off. For instance, Kin would leave in the middle of class and randomly end up in the schoolyard. Also, he oddly started saying that his brothers were conspiring against him. Two years after these first signs at the age of 18 years old, Kin was diagnosed with schizophrenia.

Undoubtedly for most of us, imagining receiving this kind of diagnostic must seem like an immense burden. Yet, for Kin's family, this can rather be seen as a kind of liberation.

Undoubtedly for most of us, imagining receiving this kind of diagnostic must seem like an immense burden. Yet, for Kin's family, this can rather be seen as a kind of liberation. Indeed, they knew something was troubling their son, but now they were better equipped with knowledge regarding what to do, what to say... in brief, to know just how best to respond to their son. Devotedly, their greatest challenge was to stimulate their son and to give him goals. In particular, they had to learn to live with the incertitude of his condition. It is at this point that they decided to live it day by day.

Following this diagnosis, Catherine and Joaquin decided not to hide the truth and above all to not live in the shadows. They therefore spoke openly about the disorder to their sons, to their family, and to their friends. Ironically, it was they who often had to reassure their entourage. The very act of talking about things allowed the family to develop a strong social network. But even though family and friends accepted Kin's circumstance, they nevertheless still felt a certain level of stigmatization from the general population. It is in this regard that they understood the importance to take the time to explain to people what the actual disorder of their son was all about in order to dispel myths.

At this time, Catherine was on a maternity leave. She had to reintegrate into the workplace some time afterwards. This turned out to be a difficult period for the whole family for several reasons. In addition to the stress of occasionally having to leave their son alone at home and not knowing what to expect upon their return, they had to now juggle a very heavily charged schedule. They had to drive Kin to the hospital for routine

appointments or had to visit him when he would be hospitalized. Throughout all of this, they also had to take care of their other three children. And how do these children live with all of this you might ask? One of Kin's brothers, Andy, mentioned that he never once felt neglected. He adds: "We are a very close family and as such understand when a family member needs a little more attention".

Even if parents are forced to live it all out day by day, it does occasionally happen to them to think about the future of their son. Presently Kin is not able to go to school nor to work. Yet his family is hopeful that one day they will see him enter the work force. Catherine and Joaquin remain very optimistic and desire to be present for their son, as long as he will need them.

"The very act of talking about it and to not hide takes a huge knot out of the stomach".

Near the end of our exchange, I asked them if they had any messages they would like to share with others. The first thing that they told me is that it is essential to accept the disorder, even if it is not always easy to accept the fact that your child is ill. And when it comes to mental disorders, it does not simplify things at all. Rather, they added: "The very act of talking about it and to not hide takes a huge knot out of the stomach". Finally, they remind us of the importance of informing and the will to understand, in order to avoid judging too quickly.

On a more personal note, I would like to take this opportunity to thank Kin's family for sharing their story. I know just how important it was for them to do so. I tip my hat in acknowledgement to them and to others who are living in similar situations and salute and commend their courage, their determination, as well as for being inspiring role models to us all. *JP*



Silent Victimes:

The Stigma of Mental Illness and the Effects of Stress on Spouses and Children of Individuals Suffering from Major Depression

Dr. Sonia Lupien and Nathalie Wan

One day, after a conference on stress that I had delivered to the general public, a woman approached me and asked a question about severe depression. While talking to her, I learned that the woman's husband had been suffering from severe, refractory depression for the last 2 years. This woman told me that she was under considerable stress, but this was nothing compared to the effects of her husband's depression on her two children. The woman reported that her oldest daughter refused to bring her new boyfriend home because she did not want him to see her dad *'like this'*.

“You know, if my husband had been paralyzed in a wheelchair, everyone around us would be understanding of our ordeal and my daughter would introduce her dad to her friends with no problem. But because my husband is suffering from a severe mental health disorder, the stress of the stigma surrounding his disorder, along with the disorder itself, is killing us all very slowly”.

The mother also reported that her younger son was changing from a cheerful child to a sad and introverted young boy. She then told me this last sentence before leaving silent: “You know, if my husband had been paralyzed in a wheelchair, everyone around us would be understanding of our ordeal and my daughter would introduce her dad to her friends with no problem. But because my husband is suffering from a severe mental health disorder, the stress of the stigma surrounding his disorder, along with the disorder itself, is killing us all very slowly”.

The inspiration for this study was sparked by this woman's story. The Centre for Studies on Human Stress dedicates the study to her, her children and husband, and the thousands of other families in this situation.

Caring for a mentally ill family member can adversely affect the health status of spouses and their children. Adding to the stress of caregiving is the stigma often placed on spouses and children of people with mental illness. Previous studies have looked at mental health stigma as it applies to adults; however, none have examined the effects of

The goal of this study is to examine the stigma of mental illness and the stress effects on spouses and children of individuals with major depression.

stigma on the children of these families. The build up of stress caused by perceived stigma can cause a chronic stress response in spouses and children of individuals suffering from a mental illness, and lead to cognitive and mental health problems in these populations. Indeed, various studies in the stress literature now show that the chronic secretion of stress hormones induced by exposure to long-term psychological stress can impact brain development and lead to increased vulnerability to cognitive and mental health problems in children. Nowadays, we are able to easily measure a person's stress levels by measuring cortisol with saliva samples.

What are the objectives of the study?

The goal of this study is to examine the stigma of mental illness and the stress effects on spouses and children of individuals with major depression. The main objective of this study is to determine whether the stigma surrounding depression has an impact on physiological and psychological markers of stress in spouses and children.

Who will be tested, and how?

During the study, we will assess physiological (stress hormone levels in saliva) and psychological measures of stress in three groups of spouses and their children. Saliva samples in both spouse and children will be taken 4 times a day for 3 days.

Three hundred male and female caregivers and their children (750 participants in total) will be recruited for this study. Participants will include:

- 1) Caregivers and children of individuals diagnosed with major depression;
- 2) Caregivers and children of individuals diagnosed with cancer, and;
- 3) Non-caregivers and their children.

Measures of salivary cortisol levels as well as psychological questionnaires will be collected in order to assess physiological and psychological stress in caregivers and their children. Questionnaires can be completed at home either paper-and-pencil style or electronically on a computer.

To be included in the study, participants need to meet the following criteria:



- 1) The spouse or partner is living with the care recipient in the same household.
- 2) The spouse is between the age of 35 and 55 years of age and has at least one biological child living in the same household
- 3) Children of spouses are between 11 and 17 years of age
- 4) Children of spouses (depression and cancer groups) must be informed about the disease of their parent.
- 5) In families where more than 1 child exists, all children above 11 years of age will be assessed upon parental consent and child's assent
- 6) In the non-caregiver group, families that do not have any member in the same household suffering from a physical or mental illness and who have at least one child between the age of 11-17.

Once all inclusion criteria have been met, participants will be met at home or at the laboratory based on their choice. During this visit, the spouse and his/her children will each receive a 'saliva kit', and will be instructed on how and when to provide the saliva samples. During this visit, the instructions to complete the questionnaires will also be explained to the participants.

What is the significance of this study?

Let's go back to the lady that I met at the conference and the thousands of other families in her situation. If we show that stigma of mental health has a significant impact on physiological and psychological markers of stress in spouses and/or their children, we will have provided data for policy makers. This could help them to put into action policies that help the *families* of those with a

People who are more familiar with mental illness through learning are less likely to have prejudices and to discriminate against individuals with mental health disorders, and experience less negative emotions when faced with this topic.

mental illness, along with the patients themselves. This will be extremely beneficial for the well-being of Canadian spouses of mentally ill individuals and their children.

This will create a call for action. Several studies now show that one of the best ways to influence attitudes towards mental illness is to provide familiarity with it. People who are more familiar with mental illness through learning are less likely to have prejudices and to discriminate against individuals with mental health disorders, and experience less negative emotions when faced with this topic. Recent studies have shown that mental health teaching programs addressed directly to children and teenagers in schools have a significant impact on decreasing stigma related to mental illness and at increasing self-reports of mental health problems. If this study shows that stigma related to mental illness has a significant impact on the physiological and psychological well-being of the children of these families, then we will have the means to act on this by creating new teaching programs to educate children and teenagers on mental health issues directly in schools, so that the children of this lady at the conference, and the thousands of children living the same situation, can return home at night with less social stigma on their shoulders to deal with.

If you are interested in participating in this study, please contact the coordinator of the study, Mrs. Nadia Durand at (514) 251-4015, extension 3240. 📞



Par amour du stress

Sonia Lupien, Ph.D., Director of the Centre for Studies on Human Stress of Louis-H. Lafontaine Hospital and professor in the Department of Psychiatry at University of Montreal has recently published her first book titled "Par amour du stress" in French only at the moment.

"Contrary to what people think, stress is not a disease: it is essential to human survival", explains the author who also directs the Fernand-Seguin Research Centre at Louis-H. Lafontaine Hospital. "On the otherhand, if you endure chronic stress, this can have dire consequences."

In this book, Sonia Lupien writes in simple style full of imagery and with a pinch of humour the combined results of 20 years of scientific studies on stress, its causes, its symptoms, and its long-term consequences on the human body. She proposes surprising methods to control it, which all of us can achieve.



Here are some scientific articles that we made reference to that might be of interest:

LEE, S., COLDITZ, G.A., BERKMAN, L.F., & KAWACHI, I. (2003). "Caregiving and risk of coronary heart disease in U.S. women: a prospective study." *American Journal of Preventive Medicine* 24, 113-119.

LEE, S., KAWACHI, I., & GRODSTEIN, F. (2004). "Does caregiving stress affect cognitive function in older women?" *Journal of Nervous and Mental Disease*, 192, 51-57.

LINK, B.G., STRUENING, E.L., NEESE-TODD, S., ASMUSSEN, S., & PHELAN, J.C. (2001). "Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses." *Psychiatric Services*, 52, 1621-1626.

STUDY ON STRESS IN CHILDREN AND SPOUSES OF INDIVIDUALS SUFFERING FROM CANCER OR DEPRESSION

Physical and mental illness can be an important stress for children and spouses of individuals suffering from disorders. The Centre for Studies on Human stress is carrying out a study to determine the presence and extent of stress experienced by children and spouses of individuals suffering from cancer or depression.

The study involves taking samples of saliva (for measurement of stress hormones) at home at different times of the day over a period of three days, for spouses and children (between 11 and 17 years of age), of individuals with cancer or depression. We also ask children and spouses to fill out various questionnaires on stress and family life.

Participating families will receive a compensation of \$30 for their involvement in this study.

If you are interested in participating in this study, please call Ms. Nathalie Wan at **514 251-4015 ext. 3252** or contact Ms. Wan by email at: nathalie.wan@crfs.rtss.qc.ca and include your name, date of birth and telephone number in your message.

This study is led by
Sonia J. Lupien, Ph.D.
of the Centre for Studies on Human
Stress, Louis H. Lafontaine Hospital
in Montreal.

www.humanstress.ca

STUDY ON STRESS IN CHILDREN AND PARENTS

Modern life involves many stressors, and these stressors can affect parents and children. The Centre for Studies on Human Stress is conducting a study to determine the presence and extent of stress experienced by children and parents.

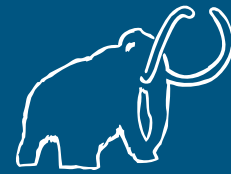
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Next issue: Manly Stress

Interesting fact: in the stress scientific literature, it seems that women report more stress. By contrast, men appear to have a larger physiological response when facing a stressor. Moreover, the consequences of chronic stress can sometime be more severe for men.

The next Mammoth Magazine will deal with stress in men that will be offered as a gift for Father's Day!



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