

New Developments for Family Caregivers in the Context of Mental Health in Canada

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ABSTRACT

In Canada, unpaid caregivers in the context of mental health are starting to receive the attention they deserve. To a certain extent, caregiving in other domains has been already recognized as an essential component of care, especially caregiving to frail elderly and those with Alzheimer's disease and dementia. Caregivers of a loved one with mental illness, however, have hardly been on the radar until recently. This report provides contextual background and a brief history of some recent, positive developments in Canada in addressing the needs of caregivers of family members who have mental health problems or illnesses. The role of family caregivers is being defined with increasing precision. Grassroots organizations and government-sponsored institutions are articulating responsive policies for bringing caregivers into the spotlight. While in its early days, there appears to be growing momentum in recognizing the crucial role family caregivers play in the recovery process in mental illness, the special needs that caregivers themselves have as a result of this role, and the economic burden of failing to accord caregivers a prominent place in any overall strategy for dealing with mental health issues on a national level.

Keywords: caregivers, caregiving, mental health, family caregivers, mental health policies

RÉSUMÉ

Au Canada, les proches aidants qui s'occupent (bénévolement) de personnes ayant un problème de santé mentale commencent enfin à recevoir l'attention qu'ils méritent. En effet, dans d'autres domaines de la santé, les soins et l'aide apportés par les proches – en particulier dans le cas des personnes âgées ayant une santé fragile ou souffrant d'Alzheimer ou de démence – sont déjà, dans une certaine mesure, reconnus comme essentiels ; mais ce n'est que récemment que l'on a commencé à s'intéresser au cas des proches qui s'occupent d'une personne ayant un problème de santé mentale. Dans cet article, je présente un aperçu de certains développements récents en cette matière. Par exemple, on observe que le rôle des proches aidants est maintenant défini avec de plus en plus de précision. Les organismes communautaires et les institutions

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subventionnées par l'État conçoivent des politiques pertinentes afin que le rôle et la situation des proches aidants soient mieux connus. Et, même si ce n'est qu'un début, on met de plus en plus l'accent sur l'apport essentiel des proches aidants dans le processus de guérison des personnes ayant un problème de santé mentale, sur les besoins particuliers des proches aidants et sur le fardeau économique qui résulte du fait qu'aucune stratégie, en matière de santé mentale, n'accorde de place importante aux proches aidants au niveau national.

Mots clés : personnes soignantes, soins, santé mentale, proches aidants, politiques en matière de santé mentale

New Developments for Family Caregivers in the Context of Mental Health in Canada

At last, in Canada, unpaid caregivers in the context of mental health are starting to receive the attention they deserve. Or so we hope. To a certain extent, caregiving in other domains has been already recognized as an essential component of care, especially caregiving to frail elderly and those with Alzheimer's disease and dementia. Caregivers of a loved one with mental illness, however, have hardly been on the radar until recently. This report provides contextual background and a brief history of some recent, positive developments in Canada in addressing the needs of caregivers of family members who have mental health problems or illnesses.

In 2013, a Statistics Canada report (Turcotte, 2013) compared, probably for the first time, different types of family caregivers based on their relationships with their primary care receivers. According to this report, in 2012 eight million Canadians, or 28% of the population aged 15 and over, provided care to family members or friends with a long-term health condition, a disability, or problems associated with aging. The study found that among regular caregivers (those who spent at least two hours caregiving each week), 8% cared for a spouse or partner and 5% for a child (including adult children). Among all caregivers to children (including adult children), the main reason for caregiving arose because of mental health problems (23%), whereas among caregivers to a spouse or partner it was the fourth reason for caregiving (7%). In the context of mental illness, the largest groups were caregivers to children and spouses. And while caregivers of older parents were more numerous, they may have been less burdened on average compared to caregivers of children (including adult children) and spouses.

The study also found that the psychological, health, financial and work-related consequences of caregiving were especially significant for caregivers of people with mental health issues. Caregivers' psychological symptoms include anxiety and worries, fatigue, anger and irritability, feeling overwhelmed, and having sleep problems. Many reported feeling that their overall health suffers as a result of caregiving, and that their financial commitment is not inconsequential. Among employed family caregivers of a spouse or child with a mental health issue, one in four had reduced hours of work due to caregiving responsibilities.

These findings corroborate an earlier study (Wrosch, Amir, & Miller, 2011) that was conducted to understand how long-term caregiving to a relative with mental illness affects the caregiver's well-being. It was found that effective coping behaviours used to address challenges presented by mental illness can moderate (or buffer) the effect of the caregiving burden on well-being outcomes. This suggests that providing proper support can help caregivers acquire effective coping behaviours and reduce the burden they experience.

In May 2015, the Caledon Institute for Social Policy announced the launch of social-architecture.ca to release a series of research papers that look at the social architecture—the suite of social programs and policies in Canada—and offer some fresh ideas on how to introduce change and renewal. Among the principal concerns are unpaid caregivers, who are described as “invaluable and invisible” in the current landscape (Torjman, 2015).

James Hughes (2015, p. 32) describes the prevalent philosophy behind most social programs in Canada. The social safety net, he claims, “is built to minimize political risk, limit financial exposure, avoid waste, and rely on the individual and family first to manage the problem in question.” Such a structure caters to the most needy while denying supports to those less needy. Effective early intervention, he claims, would recognize problems long before they reach crisis proportions, would prevent many crises, and be of benefit not only to the supported individuals and their families, but also to the health and social services system. Caregiving is just one area that, had it been addressed earlier and better, could have proved to be more effective and less costly.

In recent years, a few new initiatives have sprung up to address the challenging circumstances of caregivers and the special needs resulting from their experiences. Among these initiatives are the *National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses* (MacCourt, 2013; henceforth, the *Guidelines*) that was developed by the Mental Health Commission of Canada and launched in June 2013. Two others are the *Canadian Employers for Caregivers Plan* (Government of Canada, 2015) and the *Mobilizing Action, Family Caregivers in Canada* project (Canadian Caregivers Coalition, 2013). These two refer to caregiving in general. Finally, there is the *National Standard of Canada for Psychological Health and Safety in the Workplace* (Standards Council of Canada, 2013; henceforth, the *Standard*) launched in early 2013, which is not explicitly aimed at caregivers but nevertheless has important implications for them.

The Canadian federal government, recognizing the serious ramifications of not supporting caregivers in the workplace, launched the *Canadian Employers for Caregivers Plan* (CECP) in 2014 (Government of Canada, 2015), which aimed at helping to maximize caregivers’ labour force participation and maintain workplace productivity. Moreover, the federal budget announced in April 2015 included several initiatives to increase support for family caregivers. However, while encouraging, these new provisions refer to disabled veterans and gravely ill family members or seniors; there is no explicit recognition of caregivers in the context of mental illness.

With 6.1 million Canadians in the workforce who were providing care to a family member or friend in 2012 (35% of Canada’s work force), it was recognized that it could be too costly to ignore the challenges associated with caregiving. The CECP, therefore, has focused on engaging with employers to identify their best practices and to use these findings to support Canadian businesses and help caregivers to enter or stay in the labour force.

The CECP plan includes the establishment of an Employer Panel for Caregivers, comprising industry leaders from small-, medium- and large-size businesses, as well as expert advisers on caregiving. They will consult with employers across Canada to help identify successful and promising workplace practices that support caregivers who are balancing their work responsibilities with caring for a loved one, to ensure a stronger workforce and more prosperous economy.

The *Standard* mentioned earlier focuses on addressing mental illness in the workplace (Standards Council of Canada, 2013). Commissioned by the *Mental Health Commission of Canada* (MHCC) and developed by the Canadian Standards Association (CSA Group) and the Bureau de normalisation du Québec (BNQ), the *Standard* presents a business case for addressing mental illness in the workplace that rests on four main parameters: enhanced cost effectiveness, improved risk management, increased organizational recruitment and retention, and corporate social responsibility. The *Standard* is a voluntary set of guidelines, tools and resources focused on promoting employees' psychological health and preventing psychological harm due to workplace factors. While the *Standard* does not target caregivers explicitly, because caregivers make up 35% of Canada's workforce, it is clearly important to apply the *Standard* to caregivers wherever possible.

The *Mobilizing Action, Family Caregivers in Canada* project mentioned earlier is aimed at identifying and stimulating actions to support family caregivers. Overseen by the Canadian Cancer Action Network, the Canadian Caregiver Coalition and the Canadian Home Care Association, the *Mobilizing Action* project includes activities to enhance awareness and recognize caregivers for their contribution, to improve access to resources and support services, to alleviate undue financial burden, to create flexible workplaces and to inform policies that focus on government support.

While two of the above-mentioned initiatives refer to caregivers only in general terms and implicitly, the *Guidelines*, mentioned earlier, focus specifically on caregivers of loved ones with mental health problems or illnesses and address the entire gamut of their needs. For that purpose, the term *family caregivers* refers to those in the circle of care, including family members and other significant people who provide unpaid support to a person with mental illness. The *Guidelines* were conceived and championed by the MHCC's former Family Caregivers Advisory Committee (FCAC). The Commission then provided the resources to transform this initiative into concrete guidelines.

Several of the recommendations for action in the MHCC's *Changing Directions, Changing Lives: The Mental Health Strategy for Canada* (the *Strategy*) that was released in 2012 directly address the role of family members and the circle of support of individuals living with mental health problems and mental illnesses (Mental Health Commission of Canada, 2012). In the *Strategy*, caregivers are recognized as important participants in the recovery journey of their loved ones and as great potential advocates for care. The *Strategy* recognizes that there is a need to strike a balance between the inclusion of caregivers in planning and facilitating care and respecting the confidentiality of the individual seeking services. The *Strategy* recommends that family caregivers be encouraged to take on more active roles in governance, accreditation, monitoring, and advisory bodies within the service system because of their interest, experience, and perspective. Finally, the *Strategy* calls for enhanced support for families so they can provide care while meeting their own needs, including increased access to respite care and more flexible work policies.

Aligned with the *Strategy*, the *Guidelines* reflect the mission of the MHCC's former FCAC, "to help create conditions that will promote full and meaningful lives for people diagnosed with mental illness and for their families and friends who often serve as their primary support network" (MacCourt, 2013, p. 2). Made up mostly of individuals with caregiving experience to loved ones with mental health problems or illnesses, the FCAC recognized that providing care and support (to someone with a mental illness) can be a daunting task. The FCAC noted that while people with mental illness are starting to receive the attention and respect they deserve, this is not consistently extended to include their families. Coupled with this, there

was a growing recognition that recovery is possible, and that with access to the right treatments and supports, people with mental illness and their communities can often flourish. However, support for families who are often in the front line of care is hardly integrated into the health care system. There is little to help them fulfill their caregiving responsibilities and sustain the integrity of their own well-being, thus families are left to fend for themselves as they try to help their loved ones recover from mental illness and at the same time keep themselves afloat. The *Guidelines* share strategies for addressing the layered needs experienced by families.

The *Guidelines* are grounded in several ideas. The first is that caregivers fulfill a distinct and important role by providing support and advocating for their ill relatives. When well supported, they can play a facilitative role in the recovery journey of their ill relative, in the improvement of their quality of life and in their inclusion in all aspects of community life. The second is that adequate support can mitigate the stressors often associated with caregiving. The absence of such support, on the other hand, can lead to negative effects that compromise caregivers' capacity to provide care, and at the same time protect their own health and well-being. Inadequate recognition and support for caregivers may generate significant emotional, physical, financial, and social burdens. When these situations create chronic stress for family caregivers, they, too, often become "collateral casualties" of mental illness. Finally, the unpaid care and support provided by family caregivers makes a major contribution to the health and social service system, which would be very costly to replace with paid formal services. Caregivers provide more than 80% of the psychiatric care needed by individuals with "long-term conditions" and it is estimated to contribute more than \$5 billion of unpaid labour annually to the healthcare system (Fast, Niehaus, Eales, & Keating, 2002). The *Guidelines* offer a template for the many types of supports and services that caregivers need at different stages of their loved one's illness and at different stages of their own lives. They are primarily aimed at system planners, policy makers and service providers in planning, implementing and evaluating mental healthcare services that recognize and address the unique needs of family caregivers.

Some of the 41 recommendations included in the *Guidelines* require relatively small adjustments or modifications in already existing programs or policies; others call for a more comprehensive evaluation and development of practices. For example, in order to address caregivers as close to a psychiatric crisis in a loved one as possible, it is recommended to "create and assign family peer navigator positions for admission and emergency areas with the role of providing direct guidance and information for family caregivers" (MacCourt, 2013, recommendation 20.1, p. 29). A project piloting this recommendation was introduced at the Douglas Mental Health University Institute in Montreal in 2011 and was subsequently integrated into regular services. While the introduction of the project faced important challenges (integrating peer support into an otherwise professional milieu can be both a threat and an opportunity!), it became evident that early support offered by a peer as early as possible is invaluable.

The publication of the *Guidelines* marks an important event in the evolution of efforts to address the needs of family caregivers of people with mental health issues. Its 41 recommendations are the culmination of a comprehensive process that included literature searches of academic journals (published between 2002 and 2012), as well as grey literature and policy documents. Canadian sources were of primary interest; however, literature from Australia, New Zealand, the United Kingdom, and the United States was also included. In addition, focus groups were held in Canada (in English in Victoria, Calgary, Thunder Bay, Toronto, and Fredericton, and in French in Quebec City) to ensure that all the important caregiving-related issues were

properly addressed. The *Guidelines* document thus presents an evidence-based, comprehensive approach to meeting the needs of family caregivers. The document identifies some universal needs of caregivers. These include caregivers' desire to know that their relatives are receiving appropriate care and have access to the services and supports that will maximize their potential for quality of life. Caregivers also need to have their relationships and caregiving roles recognized by mental health service providers and to be meaningfully involved in assessment and treatment planning. Caregivers want to receive information and timely support from knowledgeable mental health service providers, including help to enhance their coping skills, so they can effectively provide care to their relatives. They also want to have their personal needs outside of their caregiving roles recognized and supported to sustain their own health and emotional well-being.

Given the broad vision expressed in the *Guidelines*, it is clear that adoption of its recommendations will require a cultural shift within and outside of the formal mental health system. Strong and committed leadership will be needed to achieve a transformed mental health system where recovery-oriented programs and services acknowledge the importance of family caregivers, support them in their caregiving role, and recognize and respond to their needs. This leadership is not the sole responsibility of those working within the formal mental health system, but also requires action on the part of other professionals within provincial, territorial, and federal governments, as well as a range of other organizations. To promote the *Guidelines* and to facilitate the implementation of its recommendations, the MHCC recently launched *Taking the Caregiver Guidelines Off the Shelf: Mobilization Toolkit* (Mental Health Commission of Canada, 2015). This toolkit is intended to support individuals, groups, or organizations in their efforts to inform and engage those with the influence or decision-making power to implement the recommendations in the *Guidelines* and encourage the incremental shift to a caregivers-friendly culture. It includes a planning guide and practical suggestions to facilitate reaching out to different target audiences. (For both the *Guidelines* and *Toolkit* see mentalhealthcommission.ca). In addition, there may also be a business imperative that helps to explain the current growing interest in caregivers, namely the recognition that continuing to ignore their needs is gradually being viewed as not an option from an economic and social point of view.

In sum, the landscape for Canadian family caregivers in the context of mental health is evolving. The role of family caregivers is being defined with increasing precision and various influential groups, including grassroots organizations and government-sponsored institutions, have begun to articulate policies for bringing caregivers into the picture. It still appears to be early days, given that this change has occurred only in the last five years or so; nevertheless, there appears to be growing momentum in recognizing the crucial role family caregivers play in the recovery process in mental illness, the special needs that caregivers themselves have as a result of this role, and the economic burden of failing to accord caregivers a prominent place in any overall strategy for dealing with mental health issues on a national level.

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