Food for thought: A dissonance between healthcare utilization costs and research funding for eating disorders in Canada*

Kayla D. Stone, PhD¹, Gina Dimitropoulos^{2,3}, PhD, Frank P. MacMaster, PhD^{1,4}

¹Departments of Psychiatry and Pediatrics, University of Calgary, Calgary, Alberta, Canada

²Faculty of Social Work, University of Calgary, Calgary, Alberta, Canada

³Mathison Centre for Mental Health, Calgary, Alberta, Canada

⁴Addictions and Mental Health Strategic Clinical Network, Alberta, Canada

Corresponding author: Kayla D. Stone, PhD, kayla.stone1@ucalgary.ca; B4-510-39, Child and Adolescent Imaging Research (CAIR) Program, Alberta Children's Hospital, 28 Oki Drive NW, Calgary, Alberta T3B 6A8, Canada

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ABSTRACT

In this commentary, we present the premise that, in Canada, mental illness research specific to eating disorders is underfunded, and many Canadians are suffering the consequences of this underinvestment. We highlight three critical aspects of eating disorders: 1) the increasingly common yet potentially life-threatening nature of eating disorders, with an onset usually during adolescence; 2) the challenges and costs to treating eating disorders, with a discussion of current hospital-related costs across Canada; and 3) the glaring discrepancy between the money spent on eating disorder diagnoses/treatment and the funding dollars granted for eating disorder research in Canada (i.e. only \$0.70 per affected Canadian in 2018). Research funding per affected individual for other psychiatric and neurodevelopmental conditions are used as comparisons (e.g. \$50.17 per affected Canadian with schizophrenia). We suggest that it is time to revolutionize treatment for individuals with eating disorders and use our resources in a more efficient and effective manner, using current neuroimaging and neuromodulation methods as promising examples. We conclude by emphasizing the need for increased research funding in the field of eating disorders in Canada, as the current research-related investments hinder progress in developing neuroscientifically-sound treatments for these populations.

Here, we will present the premise that, in Canada, mental illness research specific to eating disorders is underfunded, and many Canadian youth, families and communities are suffering the consequences of this underinvestment.

First, eating disorders are common and potentially life threatening. It is estimated that more than 1.7 million Canadians suffer from an eating disorder at any given time (Galmiche et al., 2019). A large majority of these individuals are female adolescents and emerging adults, with most first-time cases occurring before the age of 25 (Volpe et al., 2016; Ward et al., 2019). If not treated early, eating disorders persist into/throughout adulthood (e.g., in approximately 33% of anorexia and bulimia nervosa patients in a 22-year follow-up study; (Eddy et al., 2017)), and often have long-term physical and psychological consequences (Keski-Rahkonen & Mustelin, 2016; O'Brien et al., 2017; Vall & Wade, 2015). Anorexia nervosa (AN), for example, is one of the deadliest psychiatric conditions (Arcelus et al., 2011), with a standardized mortality ratio of 5.86 (across all age groups). Rates of suicide in this population are high: a meta-analysis on mortality rates in individuals with eating disorders revealed that 1 in 5 (20%) cases of AN resulted in suicide (Arcelus et al., 2011). However, if diagnosed between the ages of 15 and 19, this ratio increases to 10. Sadly, the standardized mortality ratio nearly doubles, to 18, if diagnosed between the ages of 20-29 (Arcelus et al., 2011). Standardized mortality ratios for other common eating disorders follow closely, such as bulimia nervosa at 1.93 and eating disorder – not otherwise specified at 1.92 (Arcelus et al., 2011). In Canada, it is estimated that approximately 1000 - 1500 individuals die from AN or bulimia nervosa each year (Woodside, 2013). This is not considering other eating disorders, or deaths due to secondary complications of an eating disorder.

Second, eating disorders are challenging and costly to treat. Response and remission rates to current treatment approaches for eating disorders is only approximately 50% (Hughes et al., 2019), with 50% of cases becoming severe and enduring (Treasure et al., 2015). Annually, eating disorder diagnoses and treatments are a costly endeavor for Canada. For context, in 2017/2018, Canada spent an average of \$24,017 per individual affected with an eating disorder, 1.79 times more than what is spent on schizophrenia (Canadian Institute of Health Information, 2020). These costs were specific only to hospital services. In the same year, the average length of stay in a hospital for someone with an eating disorder was 33.5 days. In Alberta alone (where our research teams reside), \$14 million per year is spent on treating and diagnosing eating disorders (Alberta Health Services, 2017). Nearly 50% (~\$6.5 million) of that total is towards pediatric cases (<18 years of age)(Alberta Health Services, 2017). In Ontario, the average cost per patient (across all age groups, 5 – 65+ years old) was \$10,022 in 2012 (de Oliveira et al., 2017). In the same dataset, for pediatric cases only (5-19 years), the average cost per patient was \$19,857, nearly three times that of an adult 20-39 years old (de Oliveira et al., 2017). These costs have only increased in recent years (e.g. \$21,128 in 2017-2018; Canadian Institute of Health Information, 2020). Using British Columbia as a final example, a 2003 study estimated long-term disability costs for a person with Anorexia nervosa in the province could range from \$2.5 million to \$101.7 million (calculated using a sensitivity analysis; Su & Birmingham, 2003). Notably, where a patient fit within this large range was estimated based on the duration of their

current illness, their gender, which provincial disability benefit level they qualified for, their insurance provider, and the number of years of long-term disability required. Importantly, the current costs of eating disorder in Canada are calculated based on diagnosed cases of eating disorders; the indirect costs of sub-clinical and undiagnosed cases are crucial to consider as well. For example, costs related to hospital stays for reasons related to diagnosed co-morbidities, visits to the clinic that resulted in a missed diagnosis, or even lost workdays and decreased productivity in the workplace in those suffering in silence (Trautmann et al., 2016).

Third, the money spent on research into eating disorders at a federal level does not reflect its impact on society. While millions are being spent on eating disorder diagnoses and treatment every year in Canada, the amount spent on research dollars for eating disorders is much more underwhelming. In 2019, the Canadian Institutes of Health Research (CIHR) support for eating disorder research equated to approximately \$0.61 research dollars spent per affected individual, taking a conservative estimate of 1.7 million Canadians with a diagnosed eating disorder. In 2018, it was \$0.59 per affected individual. Social Sciences and Humanities Research Council of Canada (SSHRC) support for eating disorder research in that same year equated to approximately \$0.11 per affected individual (2019 numbers have not yet been made public). Averaged from 2014-2019, SSHRC support was \$0.08 per affected individual. CIHR research funding averaged over the past 5 years was \$0.65 per affected individual. Total CIHR funding in 2019-2020 for projects (that included “eating disorder” as a key word) equated to \$1,065,131. These numbers are in stark contrast to the funding provided for other psychiatric or neurodevelopment disorders that year, such as schizophrenia (\$16,926,811; approximately \$47.01 per affected individual) and bipolar disorder (\$4,245,604; approximately \$7.78 per affected individual), and autism (\$20,168,663; approximately \$53.22 per affected individual). Total SSHRC funding for 2019-2020 have not yet been made public but see table 1 for total funding from 2014-2019 for each aforementioned disorder. Murray, Pila, Griffiths, and Le Grange (2017) observed that research dollar funding for eating disorders in the United States was \$0.73 USD per affected individual. Reasons for these low funding rates are not known. We hypothesize that they could be due to several (non-mutually exclusive) factors, such as 1) gender biases (i.e. biases towards women, who are often disproportionately affected by (certain) eating disorders compared to men (Hoek, 2006; Smink et al., 2012), alongside male biases in the perception of eating disorder severity (Mond & Arrighi, 2011)), 2) priorities on who is available to review (fewer researchers in the field mean fewer expert reviewers for funding applications), 3) the chronic and obstinate nature of eating disorders (limited progress in treatment leads to limited funding and vice versa), and 4) implicit biases in perception (i.e. the perception that eating disorders are not “real” disorders) combined with lack of education on the factors that contribute to eating disorders (Blodgett Salafia et al., 2015; Mond & Hay, 2008). Thus, whether low funding rates for eating disorder research are attributable to these reasons would be an interesting area for future research.

Table 1. Canadian research funding for specified psychiatric and neurodevelopmental disorders (2014-2019).

Funding agency	Year	Eating Disorders	Schizophrenia	Bipolar Disorder	Autism
CIHR	2014	\$764,559	\$16,045,050	\$2,925,917	\$12,096,982
	2015	\$1,161,122	\$14,774,889	\$2,555,932	\$15,237,926
	2016	\$1,589,391	\$15,089,923	\$3,162,220	\$18,936,469
	2017	\$790,031	\$16,310,910	\$3,043,827	\$15,176,843
	2018	\$1,024,224	\$17,848,051	\$3,994,919	\$18,889,692
	2019	\$1,065,131	\$16,926,811	\$4,245,604	\$20,168,663
SSHRC	2014	\$90,000	\$0	\$0	\$629,445
	2015	\$107,500	\$17,500	\$35,000	\$593,836
	2016	\$105,000	\$52,500	\$35,000	\$1,699,272
	2017	\$172,500	\$70,000	\$35,000	\$2,008,386
	2018	\$195,000	\$212,500	\$0	\$2,829,176
	2019	N/A	N/A	N/A	N/A
CIHR + SSHRC	Total (2014-2018)	\$5,999,327.00	\$80,421,323.00	\$15,787,815.00	\$88,098,027.00
	Average/year	\$1,199,865.40	\$16,084,264.60	\$3,157,563.00	\$17,619,605.40

Note. Total funding was obtained from the CIHR and SSHRC's public databases (2014-2019). Projects that included the name of the specific disorder (e.g. "eating disorder(s)" or "schizophrenia") as a keyword or within the title of the funded project were included. N/A: Not Available.

The combination of these factors with an urgent need for further research in this space presents an opportunity for the creation of collaborative groups across Canada (and internationally) focused on eating disorder research and treatment. It is time to revolutionize treatment for individuals with eating disorders and use our resources in a more efficient and effective manner, considering the individual's immediate and extended support systems, as well as cultural, environmental, and social factors. Our suggestion is for the creation of a key stakeholder research group that brings together policy makers, providers, researchers from different fields, people with lived experience and caregivers. We would like representation from key informants and stakeholders to ensure that there is an opportunity to generate new ideas for addressing the genetic to clinical issues. See figure 1 for a depiction of this.

Multifaceted approach to supporting eating disorder patients

Figure 1. Multifaceted approach to supporting eating disorder patients. Graphic depiction of a multifaceted approach to better support the patient and advance our understanding of eating disorders. Proposed teams are included in each bubble. The innermost bubble depicts the patient's immediate contacts and support system. Remaining bubbles include supports that move from more direct to indirect connections with the patient. Ideally, teams from different bubbles will work together.

Current (common and well-established) treatments for eating disorders involve psychotherapies and/or medications. For example, family-based therapy (or FBT) is the most effective treatment available for adolescents with anorexia nervosa. FBT is a form of therapy wherein the parents/caregivers play a central role in the recovery process, and has been shown to be superior to individual therapy, particularly at 6-12 months posttreatment (Couturier et al., 2013; Lock et al., 2010). Aligned with this, FBT is strongly recommended by the recently developed Canadian practice guidelines for the treatment of children and adolescents with eating disorders (Couturier et al., 2020). However, clinical response rates to any one therapy (e.g., FBT with response rates of ~35-50%; (Hughes et al., 2019; Le Grange et al., 2014)) or cognitive behavioural therapy for adolescents with bulimia nervosa (Schmidt et al., 2007)), or

medication alone are not 100%. How can we better improve response rates to current treatment approaches, such as FBT? Undoubtedly, novel work in multiple directions is needed.

Aligned with this, we know that methods in neuroscience and psychiatry have improved substantially in the past 20 years. For example, transcranial magnetic stimulation is a form of non-invasive brain stimulation that can change brain activity and function in parts of the brain (Klomjai et al., 2015). There is evidence for its effectiveness in individuals with treatment-resistant Major Depressive Disorder (Gaynes et al., 2014; McClintock et al., 2018) and is a promising treatment for many other psychiatric and neurodevelopmental disorders (Cirillo et al., 2019; Hsu et al., 2018; Lusicic et al., 2018). Thus, combining neuroimaging techniques (like magnetic resonance imaging and spectroscopy) with neurostimulation paradigms could transform our understanding of eating disorders. Such investigations are emerging in the field of eating disorders (Jáuregui-Lobera & Martínez-Quinones, 2018; Van Den Eynde & Guillaume, 2013), but these investigations, particularly in Canada, are still limited, and perhaps not yet well enough supported by the evidence. We therefore could focus our efforts on funding research that combines current and well-established therapies, such as family-based therapy (Couturier et al., 2013; Doyle et al., 2010; Lock et al., 2010), with novel neurostimulation and neuroimaging techniques to potentially accelerate clinical response. Such opportunities will allow us to refine and strengthen current approaches, while also advancing our understanding of novel therapies. Ultimately, this could lead to the development of personalized treatment plans for individuals with eating disorders.

Thus, with increased funding opportunities, Canada could be at the forefront for uncovering these (still unknown) mechanisms that underlie eating disorders, and in the advancements of tailoring treatment approaches accordingly. Overall, it could better revolutionize care for the affected individuals, and their families alike. A recent Canada-wide survey on research priorities for eating disorders revealed that the top need was effective treatment options, including a better understanding of the biology of eating disorders and predictive elements of treatment (Obeid et al., 2020). Unfortunately, the current research-related investments hinder progress in that domain. The breakdown of these research-related investments by major granting agencies in Canada, by factors such as the age of the research population being studied (i.e., pediatric, young adults, older adults), is not readily available in the public datasets as they exist. Moreover, these granting agencies do not routinely (or publicly) publish which proposed projects do not receive funding each year. These pose limitations to the interpretation of this dissonance between researcher funding and healthcare utilization costs. As a call to action, we suggest these agencies publish aggregate data (as not to identify individual/team applicants) on the number of applications submitted to the granting agency, organized by funding status, proposed medical condition, and population type (e.g., age).

In conclusion, by every measure, the cost to society, impact on the individual, and risk of death from eating disorders is on par with serious mental illnesses like schizophrenia, but the level of research investment pales in comparison (see figure 2). So, we must ask ourselves: what is lost when we consider the current cost of eating disorders?

A. Eating Disorders and Schizophrenia: Prevalence, Standardized Mortality Ratio, Health Care Spending, and Federal Funding per Individual

B. Eating Disorders as compared to Schizophrenia: Prevalence, Increased Risk of Death, Health Care Spending, and Federal Funding

Figure 2. A) Eating Disorders and Schizophrenia: Prevalence, Standardized Mortality Ratio, Health Care Spending, and Federal Funding. From left to right, bar graphs depicting prevalence, increased risk of death (standardized mortality ratio), health care spending per individual (hospital costs, calculated by CIHI 2017-2018), and CIHR plus SSHRC funding dollars per affected individual in 2018-2019. Blue bars represent eating disorders (or anorexia nervosa in second graph from left); orange bars represent schizophrenia B) Eating disorders as compared to schizophrenia. Visualization of the increased prevalence, risk of death, health care spending, as well as the proportion of research dollars spent on eating disorders compared to schizophrenia.

Conflicts of Interest

The authors declare that they have no conflicts of interest to disclose.

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