

# Benefits and barriers to engagement of mental health caregivers in advisory roles: Results from a cross-sectional survey

Cynthia Clark<sup>1,2</sup> | Alexis Dorland<sup>1</sup>  | Natalia Jaworska<sup>1,3,4</sup> |  
Robyn J. McQuaid<sup>1,3</sup> | Michèle Langlois<sup>2</sup> | Florence Dzierszinski<sup>1</sup>

<sup>1</sup>Institute of Mental Health Research, University of Ottawa, Ottawa, Ontario, Canada

<sup>2</sup>The Royal Ottawa Mental Health Centre, Ottawa, Ontario, Canada

<sup>3</sup>Department of Neuroscience, Carleton University, Ottawa, Ontario, Canada

<sup>4</sup>Department of Cellular Molecular Medicine, University of Ottawa, Ottawa, Ontario, Canada

## Correspondence

Alexis Dorland, 1145 Carling Ave, Room 5427, Ottawa, ON K17 7K4, Canada.  
Email: [alexis.dorland@theroyal.ca](mailto:alexis.dorland@theroyal.ca)

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## Abstract

**Background and Aims:** Mental health institutions and community organizations have had difficulty recruiting patients and caregivers onto their Patient, Family, and Community Advisory Committees (PFACs). Previous research has focused on barriers and enablers of engaging patients and caregivers who have advisory experience. This study acknowledges the experiential difference between patients and caregivers by focusing only on caregivers; further, we compare the barriers and enablers between advising versus non-advising caregivers of loved ones with mental illness.

**Methods:** Data from a cross-sectional survey codesigned by researchers, staff, clients, and caregiver affiliated with a tertiary mental health center were completed by  $n = 84$  caregivers ( $n = 40$  past/current PFAC advising caregivers;  $n = 44$  non-advising caregivers).

**Results:** Caregivers were disproportionately female and late middle-aged. Advising and non-advising caregivers differed on employment status. There were no differences of the demographics of their care-recipients. More non-advising caregivers reported being hindered from PFAC engagement by family-related duties and interpersonal demands. Finally, more advising caregivers considered being publicly acknowledged as important.

**Conclusions:** Advising and non-advising caregivers of loved ones with mental illness were similar in demographics and in reporting the enablers and hindrances that impact PFAC engagement. Nevertheless, our data highlights specific considerations that institutions/organizations should consider when recruiting and retaining caregivers on PFACs.

**Patient or Public Contribution:** This project was led by a caregiver advisor to address a need she saw in the community. The surveys were codesigned by a team of two caregivers, one patient, and one researcher. The surveys were reviewed by a group

Cynthia Clark and Alexis Dorland are cofirst authors.

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of five caregivers external to the project. The results of the surveys were discussed with two caregivers involved directly with the project.

#### KEYWORDS

advisor, caregiver, council, family advisory council, mental health

## 1 | INTRODUCTION

Engaging patients and caregivers in the governance and evaluation of health services has become an increasing priority within the healthcare system.<sup>1-3</sup> To facilitate these engagement efforts, many health institutions and community organizations have created what are typically referred to as Patient, Family, and Community Advisory Councils (PFACs). In the context of tertiary healthcare centers, patients and caregivers are recruited into PFACs to advise on a variety of topics, including strategic planning of hospital directions, quality improvement in patient services, advising on research aims and directions along with feedback on existing research projects within the research hospital, and staff training that integrates a “client lens.”<sup>4</sup> Members recruited onto PFACs as advisors are typically expected to represent the interests of the larger population of patients and caregivers of the hospital/institution they are affiliated with.<sup>3,5</sup>

Recruiting advisors for such positions, is a challenge faced by many healthcare organizations as they are unable to find patients and caregivers who are suitable and willing to become advisors for PFACs.<sup>6,7</sup> The process of advisor recruitment in itself along with existing barriers that hinder participation (both perceived and real) in an advisory role have not been well described in previous studies; the same is true of facilitators that promote PFAC engagement.<sup>8</sup> Difficulties associated with recruitment into advisory roles onto PFAC councils can lead to under-representation of patient and family populations. This results in organizations less likely or unable to address the needs of their entire patient and family user base.<sup>5,9</sup> For instance, representation from minority racial and ethnic groups is necessary to improve health disparities and ensure care is more equitable.<sup>10</sup> These and other concerns are echoed by patients and family members not involved with PFACs as they strongly feel that their own personal needs should be adequately represented on the council.<sup>11,12</sup> However, there is virtually no work examining perceived benefits and existing barriers for patients and family members who participate in PFACs, as well as the characteristics (e.g., demographics) of such members (i.e., a comprehensive characterization of this group is lacking). Further, there has been no comparison of the motivations and characteristics of those who are already serving in advising roles versus those who are not, but, may be interested in doing so.<sup>11,12</sup> Such insight is important to determine that adequate representation is present on advisory councils and, if not, what barriers may be limiting a particular population subgroup for participatory roles along with associated benefits. Further, such data would be helpful in identifying targeted recruitment strategies for PFACs by institutions. By comparing the demographic and

motivational differences between caregivers with and without PFAC experience, this study intends to highlight existing deficiencies that likely prevent proper representation.

Previous studies on PFAC members have been focused on characterizing patient, or combining patient and caregiver, perspectives<sup>2,8</sup>; however, merging caregiver and patient perspectives may obscure important information. Specifically, caregivers and patients have uniquely different experiences, needs, and views that contribute different perspectives in the context of PFAC roles.<sup>13-15</sup> In other words, these differences might be fundamental to informing their advisory work, and enriching the organization. For example, the definition of “recovery” from severe mental health issues differ between patients and their family members,<sup>16</sup> which likely influence their expectations of the healthcare system and treatment. This, in turn, may determine what perspectives such individuals bring in their role as advisors on PFACs along with their contributions. Given that PFACs might ultimately alter some of the strategic directives of a hospital, including care and research, this is an important consideration. As such, given the dearth of research on the subject, the current study focused on characterizing the features of caregivers in advisory roles as well as those in non-advisory roles. Specifically, it aimed to examine their individual perceptions on the benefits, barriers, and expected outcomes from participating on PFACs. Within the caregiver population, it was found that the experience of caregiving is highly dependent upon the illnesses of the loved one (i.e., care recipient)<sup>17</sup> (we will use the term “loved one” in lieu of care recipient in this paper, as this is the term endorsed by caregivers involved with this project). For example, caregivers of loved ones with mental illness, in particular, face hardships less likely experienced by other caregivers (i.e., those caring for individuals with medical/somatic conditions), including poorer physical health, poorer mental health, and increased interpersonal problems.<sup>18-20</sup> Further, caregivers of loved ones with severe mental illness, in particular, have reported a myriad of more pronounced physical complications than non-caregivers, including sleeplessness, headaches, and extreme tiredness.<sup>19</sup> These factors are important to characterize and consider as they might prevent caregiver engagement in PFAC/advisory roles, especially in caregivers of loved ones with severe mental illness. Failing to understand the multifaceted nature of caregiver and patient experiences in previous research might be a limitation in determining organizational factors that are important “enablers” for PFAC engagement. In this context, “enablers” are factors that allow for and/or improve meaningful collaboration between institutions and advisors. Previous research (combining caregivers and patient perspectives or not including the caregiver perspective) has

highlighted that important enablers for PFAC engagement include factors such as: creating a trusting environment, allowing equal partnerships, providing feedback about involvement, accommodating additional needs, providing accessible communication, and producing meaningful results.<sup>2,21–25</sup> It is unclear whether such aspects would be equally important to caregivers. Challenges that prevent advisory role engagement, typically referred to as “hindrances,” include feeling unwell, lack of compensation, limited availability for scheduled meeting times, inadequate communication, and lack of a dedicated team member to manage engagement.<sup>24,26,27</sup> Again, it is unclear if the same hindrances are applicable to caregivers as research on their unique perspectives regarding PFAC engagement is lacking. In the current study, we conducted a cross-sectional assessment on the PFAC role of advising caregivers of loved ones with serious mental health issues in Ontario to better characterize group demographics and identify engagement hindrances and perceived enablers. We also assessed whether differences existed in perceived engagement barriers and considerations between current mental health caregiver advisors/PFAC members compared to non-advising mental health caregivers (i.e., caregivers not on PFAC). To accomplish this, we asked caregiver advisors and non-advising caregivers which potential barriers prevented or hindered their engagement, and if certain benefits were important when considering becoming a caregiver advisor. This was performed using an online survey that was codesigned with family advisors on PFAC at a tertiary psychiatric research hospital. By understanding the components that motivate and hinder engagement, we hope to inform policies and strategies that could help mitigate identified barriers in the future, and foster an atmosphere that would encourage more caregivers to become advisors in the mental health sphere, and beyond. To our knowledge, we are the first study to include the perspectives of both advising and non-advising caregivers.

## 2 | MATERIALS AND METHODS

### 2.1 | Survey development

An environmental scan was conducted on previous research and publicly available knowledge resources focused on facilitating caregiver advisor collaboration within general healthcare settings. This included using web-searches for peer-reviewed publications (e.g., Google Scholar) and conducting a gray literature search (all data up to and including 2020). Each article was reviewed by two team members (A. D. and M. L.) to determine relevance of the material by subjective examination (i.e., based on experience sitting on PFACs in a tertiary mental health institute). Given that the original intent of this work was to create knowledge products for public use ([www.engagetcaregivers.ca](http://www.engagetcaregivers.ca)), this was not an exhaustive literature search. A report summarizing the final 14 items from the environmental scan (available on the website) selected by the team members was provided to the survey development team. Gaps and recurring topics/themes which emerged were used to develop survey

questions (details below), which were codesigned by the authors, caregivers of loved ones living with mental illness, and mental health service providers experienced in working with caregiver advisors. Two separate surveys were created: one for current/former caregiver advisors (referred to as “advising caregivers”) and another for non-advising caregivers (i.e., caregivers who have never participated in advising roles). Five external caregiver advisors affiliated with our organization (who did not complete the survey) reviewed the surveys to ensure language and content was accessible and representative of their needs. Surveys were piloted within these groups to ensure survey length was within 15 min to minimize the burden of survey participation. Surveys were accessed through two separate anonymous links hosted on Qualtrics software (Qualtrics) from October 16, 2020 to November 30, 2020. Survey links were distributed through personal networks by e-mail and published invitations on public channels, such as the Evidence Exchange Network (EENet; devoted to knowledge translation regarding mental health and additions in Ontario, Canada) and Facebook advertisements. By using anonymous public links, survey response rates could not be determined. Further details about this study can be found in our public report.<sup>28</sup>

### 2.2 | Inclusion criteria

To participate in the survey, eligibility criteria included: (1) participants who were at least 16 years of age (age of consent to participate in research in the province of Ontario, Canada, where this work was conducted), (2) ability to access the online survey, and (3) reside in Ontario, Canada, at the time of survey completion. Ability to read and understand English was an implicit inclusion criterion as the survey was in English. Participants must have also been a caregiver (current or past), such as a family member or close friend who assists/assisted a person living with mental illness. An advising caregiver was defined as a caregiver who is/had been formally involved with a hospital, community organization, or government agency in Ontario to inform on any level of the organization's operations in a variety of positions, such as working groups or steering committees (e.g., membership on PFAC, or equivalent). No restrictions existed regarding the length of time since the start of a caregiver advisor position(s). Caregivers with no advisory experience were considered “non-advising caregivers.”

### 2.3 | Measures

Caregivers completed demographic questions regarding their age, gender, first half of their postal code, current employment status, and highest level of education. They were asked to complete demographic information about their loved one (i.e., whom they are caregiver to), including their relation to their loved one, their loved one's diagnosed mental health condition, if their loved one lived with them, and how far their loved one was along their road to recovery. To compare reasons that may have hindered

participation in PFACS, advising caregivers were asked: "how much have the following personal challenges hindered your work as a caregiver advisor?"; while non-advising caregivers were asked: "how much have the following personal challenges prevented you from becoming a caregiver advisor in the past?." Both questions included the following response options: "not at all," "slightly," "moderately," and "severely." Items rated as "moderately" and "severely" were combined for the purposes of analyses. The items included: career, volunteering, or work demands; family-related duties and interpersonal relationship demands; personal physical health; personal mental health; financial limitations; language or cultural barriers; prior trauma with the mental healthcare/hospital system; and stigma related to my loved one's condition. To identify possible enablers, participants were asked: "how important were/would the following considerations be when deciding to become a caregiver advisor?" on a scale from "not important," "slightly important," "important," to "very important." Items rated as "important" and "very important" were combined for the purposes of analyses. The items included: being offered a flexible meeting schedule; having direct expenses reimbursed (e.g., parking); receiving monetary compensation; receiving tokens of appreciation (e.g., agency email address); being paired with an experienced caregiver advisor mentor; working in a welcoming and accommodating environment; being given opportunities to be matched with suitable and interesting tasks; being publicly acknowledged in reports and communications; and being given meaningful feedback.

## 2.4 | Data analysis

For all survey items, advising caregivers and non-advising caregivers were compared using two-sided Fisher's exact tests (SPSS Statistics for Windows; version 27, IBM Corp.). A significance level of  $\alpha = 0.05$  was used for each individual test. A Fisher's exact test was selected as it recommended for small sample sizes of tests with low cell counts,<sup>29</sup> as was the case in the current study. The analyses conducted for this cross-sectional study were prespecified. Participants who had not completed at least 10% of the survey were removed from the sample ( $n = 32$ ). Participants with missing data were included within the sample when possible ( $n = 1$  for survey items,  $n = 6$  for demographic information). Based upon recommendations made by our external caregiver advisors, demographic information was included as the last section of the survey and contains the highest percent of missing answers.

When analyzing demographic information, advising caregivers and non-advising caregivers were compared based upon the distribution of their population. No additional subgroup analyses were conducted. The null hypothesis for each demographic item assumed that no differences existed between the distribution of the two samples.

Hindrances to engagement were analyzed by comparing the proportion of caregivers who reported being moderately or severely

hindered by the survey item between advising and non-advising caregivers. Enablers to engagement were analyzed by comparing the proportion of caregivers who reported the survey item as important or very important between advising and non-advising caregivers. The null hypothesis for each individual item assumed that no differences existed between the advising and non-advising caregiver groups for the portion of the sample who reported hindrance/importance.

## 3 | RESULT

### 3.1 | Demographics

#### 3.1.1 | Caregiver sample

Of the 116 surveys initiated, 84 were completed (completion rate of 72%). The demographics of sample of caregivers are presented in Table 1. The sample comprised of 84 individuals total, of which  $n = 40$  were advising caregiver (*mean age* = 62 years, *SD* = 10) and  $n = 44$  were non-advising caregivers (*mean age* = 58 years, *SD* = 11). Of the sample, two caregivers and three non-advising caregivers did not provide an answer for their age. Advising caregivers and non-advising caregivers were significantly different in their employment status ( $p = 0.02$ ). Given that individual cell counts were low, statistical analyses were not carried out. However, qualitatively, 15% of advising caregiver compared to 36.4% non-advising caregivers reported being employed full-time. On the other hand, 25% of advising caregiver and 6.8% of non-advising caregivers reported being employed part-time more. There were no differences between non-advising caregivers and advising caregiver on highest education level. Due to limited male survey responses, we could not analyze gender differences; notably, the overwhelming majority of caregivers were female (95% advising caregivers; 77.3% non-advising caregivers).

#### 3.1.2 | Loved one of caregiver

The demographics of the loved one living with mental illness are presented in Table 2. There were no differences between advising and non-advising caregivers on demographic features of the loved one whom they are/were caregivers to, including relation to caregiver, diagnosis, living with caregiver, or stage of recovery.

### 3.2 | Hindrances to engagement

Challenges that at least "moderately" hindered caregiver advisor involvement are presented in Table 3. When asked which challenges hindered or prevented their involvement as a caregiver advisor, significantly more non-advising versus advising caregivers reported being hindered by family-related duties and

**TABLE 1** Demographics of caregivers who participated in the online surveys (N = 84).

Demographic	Advising caregivers (n = 40)		Non-advising caregivers (n = 44)	
		Valid %		Valid %
<b>Gender</b>				
Male	1	2.5	7	15.9
Female	38	95.0	34	77.3
Other	0	0.0	0	0.0
Missing	1	2.5	3	6.8
<b>Employment status</b>				
Unemployed	1	2.5	1	2.3
Full-time employment	6	15.0	16	36.4
Part-time employment	10	25.0	3	6.8
Retired	12	30.0	10	22.7
Volunteer	5	12.5	1	2.3
Other	5	12.5	9	20.5
Missing	1	2.5	4	9.1
<b>Highest education level</b>				
High school completed	3	7.5	1	2.3
Some college/ university	3	7.5	5	11.4
College or university	33	82.5	35	79.5
Missing	1	2.5	3	6.8

interpersonal demands. There was also a difference between advising caregivers and non-advising caregivers citing personal physical health as a reported hindrance. No other reported hindrances/potential challenges significantly differed between advising caregiver and non-advising caregiver groups.

### 3.3 | Enablers for collaboration

Organizational benefits and qualities (i.e., enablers) that were reported as important or very important are presented in Table 4. For most enablers, there were no significant differences between caregiver advisors and non-advising caregivers ( $p > 0.05$ ). However, more advising caregivers versus non-advising caregivers agreed that being publicly acknowledged in reports was important ( $p = 0.02$ ); though this should be interpreted with caution due to low cell counts (though Fisher's tests are an appropriate choice for dealing with low cell counts), and a lack of correction for multiple comparisons.

**TABLE 2** Demographics of caregivers' loved one living with a mental illness.

Demographic	Advising caregivers (n = 40)		Non-advising caregivers (n = 44)	
		Valid %		Valid %
<b>Relation to caregiver</b>				
Parent	7	17.5	3	6.8
Spouse	2	5.0	7	15.9
Children	22	55.0	20	45.5
Sibling	2	5.0	1	2.3
Other	6	15.0	10	22.7
Missing	1	2.5	3	6.8
<b>Diagnosis(es)</b>				
Mental illness	30	75.0	30	68.2
Substance use disorder and/or concurrent disorders	6	15.0	10	22.7
No formal diagnosis	3	7.5	1	2.3
Missing	1	2.5	3	6.8
<b>Live with caregiver</b>				
Yes	18	45.0	26	59.1
No	14	35.0	11	25.0
Sometimes	7	17.5	4	9.1
Missing	1	2.5	3	6.8
<b>Recovery status</b>				
In-crisis	3	7.5	3	6.8
In progress	9	22.5	14	31.8
Complete but on- going care required	13	32.5	9	20.5
Is not participating	1	2.5	5	11.4
Other	13	32.5	10	22.7
Missing	1	2.5	3	6.8

## 4 | DISCUSSION

### 4.1 | Summary

Our investigation centered on characterizing caregivers of loved ones with mental illness. Using a participatory approach, we developed a survey to assess potential differences between advising and non-advising caregivers with respect to their demographics, and perceived barriers to and benefits of engaging in PFACs. In our analysis, we found that there were no glaring demographic differences between advising and non-advising caregivers, apart from employment status. There were a handful of differences to the perceived barriers and

**TABLE 3** Advising caregivers and non-advising caregivers' opinions on challenges that hindered their involvement.

Challenges that at least moderately hindered caregiver advisor involvement	Advising caregivers N = 40 (valid %)	Non-advising caregivers N = 44 (valid %)	Fisher's exact test
Career, volunteering, or work demands	20 (50.0%)	30 (68.2%)	$p = 0.12$
Family-related duties and interpersonal demands	18 (45.0%)	39 (88.6%)	$p < 0.01$
Personal physical health	5 (12.5%)	13 (29.5%)	$p = 0.07$
Personal mental health	5 (12.5%)	12 (27.3%)	$p = 0.11$
Financial limitations	9 (22.5%)	11 (25.0%)	$p = 0.80$
Language or cultural barriers	1 (2.5%)	1 (2.3%)	N/A—too few responses
Prior trauma with mental healthcare/hospital system	6 (15.0%)	9 (20.5%)	$p = 0.58$
Stigma related to loved one's condition	9 (22.5%)	11 (25.0%)	$p = 0.80$

Organization benefits and qualities that were reported as important or very important	Advising caregivers N = 40 (valid %)	Non-advising caregivers N = 44 (valid %)	Fisher's exact test
Working in a welcoming and accommodating environment	37 (92.5%)	40 (90.9%)	$p = 1.00$
Being given opportunities to be matched with suitable and interesting tasks	35 (87.5%)	38 (86.4%)	$p = 1.00$
Being given meaningful feedback	34 (85.0%)	37 (84.1%)	$p = 1.00$
Flexible meeting schedule	27 (67.5%)	37 (84.1%)	$p = 0.12$
Direct expenses reimbursed (e.g., parking)	25 (62.5%)	23 (52.3%)	$p = 0.38$
Being paired with an experienced caregiver advisor mentor	25 (64.1%)*	28 (63.6%)	$p = 1.00$
Being publicly acknowledged in reports and communications	12 (30.0%)	4 (9.1%)	$p = 0.02$
Receiving tokens of appreciation	11 (27.5%)	8 (18.2%)	$p = 0.43$
Receiving monetary compensation	9 (22.5%)	14 (31.8%)	$p = 0.46$

Note: \*Missing data ( $n = 1$ ).

**TABLE 4** Advising caregivers' and non-advising caregivers' opinions on organizational considerations for becoming involved.

benefits to PFAC engagement between advising and non-advising caregivers. These results are described below.

## 4.2 | Demographics of caregivers

In terms of sample representation, the average age of our two sample populations aligns with the results reported by Statistics Canada (2020) wherein caregivers, albeit not limited to mental health caregivers, were most commonly between the ages of 46 and 65 years.<sup>30</sup> Previous research investigating all (i.e., not solely mental health) PFAC advisors that included both clients and caregivers

ranged in age from 41 to over 65 years old, which also aligns with our sample's characteristics.<sup>12,21,31</sup> The level of education reported in our study also matched previous studies, wherein 73%–78% of advisors have completed some form of university or college level education.<sup>12,24,31</sup>

Of the caregivers surveyed, the vast majority were female. These results are consistent with the gender distribution reported in previous research wherein caregivers for those with mental illness, specifically, are known to be primarily female (82%–88%).<sup>18,20,32</sup> This gender distribution differs from the general population of caregivers where 54% of caregivers were female.<sup>30</sup> Interestingly, other work has noted a gender imbalance in caregivers of loved ones with rare conditions

(i.e., 79% female vs. 57% female for those with chronic conditions).<sup>24</sup> Previous studies investigating some of the reasons as to why caregivers of loved ones with mental illness and the elderly are primarily female, as supported by the current work, have provided several insights; reasons include expectations of traditional gender roles, segregation of labor, and role-socialization.<sup>32</sup> The observed gender disparities (disproportionately females) of caregivers of loved ones with mental illness, regardless of whether they are/are not advisors, is not unique. Previous research revealed that PFAC members in other domains are primarily female, although these samples include both patients and caregivers where one study investigating PFACs for general illnesses found that their sample consisted of 74% females.<sup>21</sup> In pediatrics, this difference was even more pronounced as 93.9% of PFAC members were female.<sup>31</sup> Future investigations should focus on gender-sensitive approaches to investigating motivations for advisory work, especially when considering that the formalized role of a caregiver advisor is related to work involving the governance of a project or organization.<sup>4</sup> Such governance work has been traditionally male-dominated.<sup>33</sup> It is feasible that greater female representation on PFACs might modify the interaction with institutional governance (i.e., perhaps leading to poorer communication as a result of discomfort in gender underrepresentation); however, this is speculative and should be further examined in the future.

### 4.3 | Characteristics of loved ones living with mental illness and interpersonal demands

Our analysis revealed no difference in the characteristics of a loved one living with mental illness between advising and non-advising caregivers. However, in our study, family-related duties and interpersonal demands were reported to significantly prevent engagement by non-advising caregivers compared to advising caregivers. This suggests that these hindrances may not be specific characteristics of their loved one and, instead, may be related to another factors (i.e., other family members), suggesting “competing” support system demands. Previous research has found similar results wherein interpersonal problems experienced by mental health caregivers were not significantly different between diagnostic categories or relationship type to their loved one, indicating that their interpersonal problems were somewhat independent of their loved one's diagnosis and relationship dynamic.<sup>20</sup> However, this warrants further investigation. After all, in the context of this study, we cannot eliminate the possibility that non-advising caregivers might be more hindered by interpersonal demands related to their loved one as our survey was not exhaustive. For instance, level of treatment adherence by the loved one (which was not assessed) might create additional complications for caregiving, thereby hindering advisory role involvement. We suggest further investigations into whether additional interpersonal demands are directly related to their loved one, or are associated with another factor, including secondary interpersonal commitments, multiple care-recipients, or a difference in caregiver qualities, such as coping mechanisms.<sup>19</sup>

### 4.4 | Employment and financial limitations

While more non-advising caregivers reported having full-time employment compared to advising caregivers (though this was not compared statistically), they did not report being statistically more hindered than advising caregivers by their career, volunteering, or work demands. This discrepancy may highlight a difference between perception and the reality of certain barriers for caregivers where they do not recognize that additional work commitments might indeed reflect less available time to engage in PFAC roles. Previous research, though not necessarily in the context of mental health, has shown that most advisors, who are patients and/or caregivers, are full-time employees.<sup>31</sup> Given the potential barrier that full-time work may have on willingness or ability to serve as advisors on PFACs, organizations might consider providing options for virtual meetings or advisory opportunities that require less time commitment to accommodate caregivers who wish to become involved but are hindered by other volunteering or work demands. In fact, a majority of our sample of caregivers considered flexible meeting schedules as an important accommodation. As such, this should be considered as a viable strategy to improve accessibility for advisor engagement by organizations. Non-advising caregivers of loved ones with mental health issues were not hindered differently by financial limitations relative to advisor caregivers. Previous studies found that a majority of advisors' household income was >\$40,000 USD,<sup>24,31</sup> which is comparable to \$54,700 USD for the median household income for caregivers as reported by another study.<sup>17</sup> While median income was not assessed in the current study, it appears that financial barriers were not a salient hindrance. This may, in part, explain why monetary compensation as an enabler was rated as “important” only by a minority of caregivers and no difference existed between caregiver advisors and non-advising caregivers with respect to the importance of monetary compensation. However, it should be noted that a majority of caregivers sampled were either working or retired, which may reflect a certain level of financial stability, thus, enabling engagement despite the lack of monetary compensation.

### 4.5 | Stigma

Stigma has been reported as a barrier in patient participation for advisory type work<sup>34</sup> and as a challenge to community involvement for mental health programs.<sup>35</sup> Approximately one-fourth of caregivers in our sample reported that stigma hindered their engagement; however, stigma was not different between advising caregivers and non-advising caregivers. This may suggest that stigma may be a hindrance for all caregivers, regardless of engagement history with PFACs. Efforts to reduce stigma might improve advisory engagement (and level of engagement) for both future and current advisors. Future studies should also consider measuring self-confidence and embarrassment as potential emotional hindrances to engagement.<sup>2</sup>

## 4.6 | Immediate and long-term enablers

Many of the enablers to advisory role participation/satisfaction suggested in previous research were considered important by the majority of our sample. These included, a welcoming environment, opportunities for providing feedback, and offering meaningful tasks.<sup>22,25,27</sup> Additional enablers, such as providing a mentor, offering reimbursement, and a flexible meeting schedule were considered important by a majority of our sample. For all of these enablers, there were no statistical differences between advising and non-advising caregivers. Nevertheless, flexibility, in particular, might be important in engaging more advisors who are currently working full-time in PFAC roles (e.g., holding meeting virtually or after typical work hours).

Similarly, advising and non-advising caregivers did not differ with respect to which enablers were regarded most/least important. For example, tokens of appreciation and monetary compensation were considered important by only a minority of all caregivers. These results suggest that organizations might wish to promote a welcoming environment over monetary compensation in advisor engagement. Further, our data provide some insight into which enablers have long-term effects for advisors (i.e., those that retain advisors and support them). Specifically, we noted some variation on immediate enablers (i.e., those that facilitate getting engaged) compared to items that could be considered long-term enablers (i.e., improve engagement once a caregiver is already involved). For example, more advising caregivers reported that being publicly acknowledged in reports was important compared to non-advising caregivers. This might represent a change that occurred as a result of being involved as an advisor, or could have been a determinant for involvement originally. A longitudinal study would best address this.

## 4.7 | Limitations

There are some limitations to the presented work. First, the large majority of caregivers were female precluding gender-based analyses. While this was expected, it reflects a lack of representation of male voices and perspectives, which could have important implications for care. Moreover, despite our recruitment efforts, the sample size was modest precluding statistical analyses among our variables that had small cell counts. Further, even significant outcomes should be interpreted cautiously as we did not correct for multiple comparisons. Nevertheless, our findings are a first-step toward filling an important literature gap, as characterizing current advising and non-advising caregivers in PFAC roles, particularly, in the context of mental health is lacking. We recommend that future studies aim to have higher recruitment over a longer period and perhaps consider spending more resources towards successful recruitment processes versus survey development (as surveys, such as ours, can now be shared with other institutions).<sup>36</sup>

## 5 | CONCLUSIONS

While advising and non-advising caregivers were largely similar in their demographic characteristics and factors that hindered or enabled engagement, some differences were highlighted, such as interpersonal demands (higher for non-advising caregivers) and the importance of public acknowledgments (higher for advising caregivers). This research highlights the characteristics and needs of caregivers of loved ones with mental illness that should be considered when thinking about strategies to bolster engagement with PFACs to create advisory councils that properly represent the caregiver population they are serving. Additional research is required to understand the motivations for female-dominance in advisory work and more nuanced characterization between advising and non-advising caregivers. Based upon our findings, however, we recommend that organizations consider prioritizing the tasks and environment they provide for their advisors to ensure the engagement is productive and meaningful.

### AUTHOR CONTRIBUTIONS

**Cynthia Clark:** Conceptualization; funding acquisition; investigation; methodology; supervision; validation; writing—review & editing. **Alexis Dorland:** Data curation; formal analysis; investigation; methodology; project administration; software; validation; visualization; writing—original draft; writing—review & editing. **Natalia Jaworska:** Conceptualization; formal analysis; methodology; validation; writing—review & editing. **Robyn J. McQuaid:** Conceptualization; formal analysis; funding acquisition; methodology; writing—review & editing. **Michèle Langlois:** Conceptualization; funding acquisition; investigation; writing—review & editing. **Florence Dzierszinski:** Conceptualization; funding acquisition; resources; supervision; writing—review & editing. All authors have read and approved the final version of the manuscript.

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### CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

### DATA AVAILABILITY STATEMENT

Anonymized data is available upon contacting the corresponding author. Alexis Dorland had full access to all of the data in this study and takes complete responsibility for the integrity of the data and the accuracy of the data analysis.



## ETHICS STATEMENT

This study was reviewed and approved by our organization's Research Ethics Board. Participants were not compensated but were ensured that a series of knowledge products would be developed from the survey results and made publicly available. All participants were required to complete a digital informed consent form before accessing the online survey.

## TRANSPARENCY STATEMENT

The lead author Alexis Dorland affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

## ORCID

Alexis Dorland  <http://orcid.org/0000-0003-1923-3341>

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