

A Qualitative Study of Caregiving to Older Adults with Depression: “Not the Person I Used to Know”

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ABSTRACT

This qualitative descriptive study aims to explore family members' perceptions and experiences as a caregiver to older adults (>65 years) with depression. The findings revealed three key themes reflecting the experiences of caregivers, including “not the person I used to know,” “my life has changed,” and “stigma of depression.” Findings suggest caregiver education is needed to assist caregivers to understand depression, provide appropriate support and care, take care of their own health, maintain participation in valued activities, and minimize the impact of stigma. The study suggests future research to expand the inclusion criteria to depression and other comorbidities.

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Keywords: caregiving, depression, older adults, qualitative; experience, stigma

RÉSUMÉ

Cette étude descriptive qualitative vise à analyser les perceptions et les expériences des membres de familles en tant que soignants auprès de personnes âgées (65 ans et plus) atteintes de dépression. Les résultats de l'étude ont mis en lumière trois grands thèmes de réflexion qui traduisent les expériences vécues par les soignants et prêtent notamment à des ressentis tels que « cette personne n'est plus celle que j'ai connue », « ma vie a changé » et « la stigmatisation de la dépression ». Les résultats suggèrent également qu'il importe d'éduquer les soignants pour les aider à mieux comprendre ce qu'est la dépression, à fournir un soutien et des soins appropriés, à prendre soin de leur propre santé, à poursuivre des activités valorisantes et à minimiser les répercussions de la stigmatisation. L'étude propose que les recherches à venir élargissent les critères d'inclusion à la dépression et à d'autres comorbidités.

Mots clés : prestation de soins, dépression, adultes plus âgés, qualitatif, expérience, stigmatisation

Following dementia, depression is the second most prevalent mental illness among older adults (>65 years; World Health Organization, 2017b), and the incidence continues to increase. Currently, approximately 7% of older adults worldwide have a clinical diagnosis of depression, and 15% of older adults experience clinically significant depressive symptoms (Fiske et al., 2009). Depression is the second leading cause of disability worldwide (Ferrari et al., 2013), and it can impact many facets of an individual's life, such as employment, social life, leisure activities, and relationship with family (World Health Organization, 2017a). Depression is frequently associated with chronic and other medical illnesses that are prevalent in the aging population. It is commonly associated with sleep disturbance (Cole & Dendukuri, 2003; Fang et al., 2019), loss of social support (Lakey & Cronin, 2008; Ren et al., 2018), cognitive decline (Butters et al., 2004; Sachs-Ericsson et al., 2005), increased mortality and suicide risk (Farrokhi et al., 2014; Gilman et al., 2017; Conwell et al., 2002) and poor treatment adherence (Fiske et al., 2009). Additionally, stigma, or negative attitudes and perceptions of depression, have been found towards older adults with depression (Scazufca et al., 2016), which may prevent individuals from seeking treatment (Barney et al., 2006) and prompt treatment discontinuation (Arrieta et al., 2013; Grenard et al., 2011). Stigma may lead others to perceive the older adult with depression as weak and unreliable, and this may result in decreases in the provision of support from others (Norman et al., 2012).

The need for caregivers is growing with the aging population, and many caregivers report health complications due to their roles and responsibilities. The majority of older adults that reside in the community rely on family members and friends (hereafter referred to as caregivers), for assistance with activities and instrumental activities of daily living (ADL and IADL, respectively; Gitlin, 2012; Schulz et al., 2020). Nearly half of Canadians (46%) aged 15 or older have provided, or are providing, assistance to a family member or friend with a long-term health condition, disability, or aging needs (Sinha, 2013). Additionally, the majority (60%) of caregivers are working in a paid position (Sinha, 2013), and their career growth is often disrupted by caregiving responsibilities (Fast et al., 2013). Studies on caregivers' experiences have revealed that they commonly reduce their time spent with friends and other family members and on leisure activities (Beesley

et al., 2011; Cameron et al., 2006; Cameron et al., 2002) and commonly report lower physical and psychological health compared to non-caregivers (Berglund et al., 2015; Smith et al., 2014).

In the literature on caregiving and depression, research has focused primarily on caregivers of younger (< 65 years) adults with depression. Findings suggest caring for a person with depression is associated with physical and mental fatigue in caregivers (Ahlström et al., 2009; L. A. M. Gonzalez et al., 2010; Radfar et al., 2014) due to the chronic and unstable nature of depression, constant vigilance, and the need for flexibility in caregivers' schedules (Hansen & Buus, 2013; Oliffe et al., 2017; Skundberg-Kletthagen et al., 2014). Caregiver reports reflect that their emotional state is sometimes dependent on the person with depression's mood, and they often experience depressive symptoms themselves (Highet et al., 2004; Muscroft & Bowl, 2000; Nosek, 2008; Radfar et al., 2014; Skundberg-Kletthagen et al., 2014). The literature also shows that caregivers can have difficulty understanding depression and living or spending time with the care recipient due to their unpredictable mood swings (Bottorff et al., 2014; L. A. M. Gonzalez et al., 2010; Skundberg-Kletthagen et al., 2014). Qualitative research of caregiver experiences indicate they wished they were more prepared and trained for their caregiving roles to provide helpful and proper support to the person with depression (Highet et al., 2004; Stjernswärd & Östman, 2008).

Older adults with depression have a variety of characteristics that may present distinct challenges to family caregivers. Older adults are more likely to have comorbidities (Divo et al., 2014) and be retired, less active, and socially isolated (Alexopoulos, 2005; Fiske et al., 2009). Past studies have focused on family members' caregiving experiences in the context of various medical illnesses in older adults (e.g., cancer, dementia), but depression is under-researched despite its high prevalence. To date, the experience associated with providing care to an older adult with depression is unclear. Therefore, this study aimed to use a qualitative descriptive approach to explore the experiences of caregivers to older adults with depression.

METHODS

Research Design

A qualitative descriptive approach was used to understand the experiences of family caregivers of older adults with depression. This approach offers rich descriptions from participants with minimal researcher interpretations (Sandelowski, 2010). As few studies currently exist on this topic, this exploratory approach was seen to be most appropriate for this inquiry.

Participants

Caregivers were eligible for this study if they were (1) an immediate family member of the care recipient, (2) currently providing assistance with at least one activity or instrumental activity of daily living per week, (3) not financially compensated, (4) being a caregiver for at least 90 days, and (5) able to communicate in English. In addition, for the family member to be eligible, the care recipient had to be (1) over the age of 65, (2) diagnosed with major depressive disorder (MDD) or persistent depressive disorder (PDD), (3) not currently hospitalized, and (4) depression had to be the primary reason for care. The requirement of at least 90 days of caregiving was to ensure they had had significant experiences as a caregiver. MDD and PDD were both included to better understand caregivers who were caring for someone with serious depression,

in terms of severity and longevity. Lastly, hospitalized care recipients were not included in the study to ensure that friends and family members were providing most of the assistance to the person with depression. Convenience sampling was employed in this qualitative research. Data collection and analysis happened concurrently, and recruitment ended once theme saturation was reached.

Recruitment

Health professionals (i.e., psychiatrists, occupational therapists, nurses, and social workers) in geriatric psychiatry and mood disorder clinics from two hospitals in Toronto, Canada identified eligible outpatients (below) and, through their clinical practice and health record database, obtained information about family members involved in their care, and asked for permission to contact their family members about the study. Baycrest Health Sciences is a research and teaching hospital for the elderly. It focuses on inpatient and outpatient care for mood disorders, and it offers programs to address caregiver stress. Toronto Western Hospital is a research and teaching hospital that specializes in depression and other mood disorders, and it offers comprehensive treatment for depression, including repetitive transcranial magnetic stimulation, psychotherapy, and innovative pharmacology. Next, the researcher contacted potential participants, explained the study in detail, and screened family caregivers to ensure that they satisfied the inclusion and exclusion criteria (below) and assessed their willingness to participate in the study. If the individual consented to participate, the researcher scheduled an in-person or telephone interview.

Data Collection

The study employed a semi-structured interview approach, and interviews were informed by Pearlin's Stress Process Model (SPM; Pearlin, 1999; Pearlin et al., 1990). Consistent with the SPM, interviews probed caregiving stressors (e.g., caregiving assistance, economic stressors, and lifestyle changes), mediators (e.g., social support and coping mechanisms) and outcomes (e.g., physical and psychological health). Interviews were guided by open-ended questions and probes that asked the participants to describe (a) care recipient's conditions, (b) caregiving history and current situation, (c) caregiver's experiences in their caring role, (d) impact of caregiving on caregiver's everyday life and well-being, and (e) caregiver's demographic information. Interview locations were selected by the participants (e.g., caregiver's home, coffee shop, clinic, telephone), and field notes were recorded by the researcher during the interviews.

Data Analysis

Interviews were digitally recorded, transcribed verbatim, and reviewed for accuracy. Braun and Clarke's thematic analysis guided data analysis (Braun & Clarke, 2006). All codes were independently generated by two researchers. In the case of conflicting codes, the two researchers compared their interpretations of the data and worked towards consensus before proceeding. Codes and relevant data were then extracted and collated, and potential themes were discussed and developed by all authors who have expertise in qualitative methods, caregiving, and mental health. Based on the content richness and relationship between each theme, they were labelled as a main theme, sub-theme, or preliminary theme. Once a satisfactory thematic map

was developed, each theme was defined, described, and their connections with each other were delineated. In addition, quotations from the interviews that captured the essence of each theme were used as examples.

Trustworthiness

Three strategies, including reflexive journal, multiple analyst triangulation, and peer debriefing, were used to enhance the rigour and trustworthiness of study findings (Anney, 2014; Morse et al., 2002; Nicholls, 2009). Journal entries, consisting of the researcher's perspectives and positions, were documented before and after each interview to increase the researcher's self-awareness regarding their background and interests. The present study also utilized multiple analyst triangulation to include perspectives of researchers and health professionals from various disciplines (e.g., occupational therapy, mental health, and psychiatry), and the authors met regularly to generate ways to present the findings. As for peer debriefing, the research findings were presented in team meetings of health professionals and researchers in Toronto to receive feedback and consider alternative interpretations of the data (Morse et al., 2002).

Ethics

The study protocol was approved by the University of Toronto and Institutional Research Ethics Boards. All participants provided written informed consent before the interview, and counselling services were available if required.

RESULTS

Eleven individual interviews were conducted over an 11-month period (February to December 2017). Data saturation was reached after nine interviews and two additional interviews were conducted to ensure saturation. The median interview duration was 43 minutes, and all care recipients had one or more comorbidities (e.g., diabetes, hearing impairment, Alzheimer's disease). Most interviews were conducted in-person, including four interviews in a private room in the hospital and four interviews in the participants' homes. Three interviews were conducted remotely (i.e., telephone, FaceTime). See Table 1 for caregivers' demographic characteristics.

Three key themes reflect caregivers' experiences. Firstly, caregivers perceived changes in the person with depression's character, and they felt their relationship with the person with depression changed as a result. Secondly, the caregiving role and responsibilities affected caregivers' lifestyle and well-being. Lastly, caregivers felt the stigma of depression that they witnessed had an impact on caregiving. The following is a description of the themes with sample quotations from participants to exemplify key points.

Table 1
Demographic Characteristics of Caregivers

Characteristic	Participants (<i>n</i> = 11)
Age (range, years)	40–73
Sex	
Female	10 (90.1%)
Male	1 (9.1%)
Caregiver's country of origin	
Canada	8 (72.7%)
United States	2 (18.2%)
Iran	1 (9.1%)
Familial relationship	
Spouses	3 (27.3%)
Adult children	7 (63.6%)
Sibling	1 (9.1%)
Family income (annual)	
Over \$100K	9 (81.8%)
\$80K to 99,999	1 (9.1%)
\$60K to 79,999	1 (9.1%)
Education	
Completed post-graduate	7 (63.6%)
Completed college or university	2 (18.2%)
Completed secondary	2 (18.2%)
Reside with the person with depression (Yes)	3 (27.3%)
Person with depression's depression diagnosis	
MDD*	8 (72.7%)
PDD**	3 (27.3%)
The person with depression having comorbidities other than depression (YES)	11 (100.0%)
Interview location	
Hospital	4 (36.4%)
Participant's home	4 (36.4%)
Remote (i.e., telephone, FaceTime, Skype)	3 (27.3%)

Note. *MDD: Major depressive disorder; **PDD: Persistent depressive disorder

“Not the Person I Used to Know”

As depression manifested in the person with depression, caregivers witnessed what they perceived to be a transformation in their personality. Although caregivers understood the changes occurred as a result of the depression, they sometimes attributed the changes to personal characteristics. These changes increased the complexity of care and required modification to their caregiving approach. Caregivers also described the impact on their family dynamic, as some described feelings of losing someone that was previously there.

Symptoms of depression. Caregivers reported that their previous experience of enjoyment in the company of their loved one had been diminished because of the person with depression’s depression symptoms. These symptoms included a low mood, lethargy, and difficulties in performing daily activities. Caregivers described the person with depression as more critical, as they frequently complained about their surroundings. Caregivers felt they were sometimes the recipients of the person with depression’s criticisms. They also thought the person with depression had difficulties in finding joy in things they previously enjoyed. Caregivers also found the person with depression to be more easily upset or irritated compared to before.

Whenever I go to the [person with depression’s] house... it feels like walking into a morgue. It really, it’s like such a depressing situation to walk into that house every week. (P7, son of the person with depression)

And just, you know, like little stuff. Like oh, I don’t know, complaining about the TV show. Just constant, you know? Like my god. Is there anything you can say something nice about? (P10, wife of the person with depression)

Caregivers thought the person with depression’s behaviour changed and reported witnessing more “self-centred” and “unappreciative” behaviours. Many caregivers felt their interactions and conversations centred around the person with depression, and that these conversations were negative in tone, composed of concerns, worries, and complaints. They felt the person with depression was less cognizant of other people’s needs, and was unable to express appreciation, demanding more help instead. Caregivers said the person with depression’s behavioural changes discouraged them from offering continued support after a prolonged period of time. Although caregivers suspected these actions were manifestations of depression, some still felt taken for granted and were deterred from interacting with the person with depression.

He can be negative. He’s also very self-centred now. Everything that’s happening has to happen around him, for him. He hasn’t been very conscious about other people’s needs or concerns, which is unlike him, because he is a very sensitive man. (P2, wife of the person with depression)

Caregivers also observed a lack of motivation in the person with depression, leading to inactivity and treatment non-compliance. Some caregivers were frustrated because they thought the person with depression was not putting in the effort to improve their situation or take care of themselves.

She has difficulties in initiating and just getting up and doing stuff. She says that she can’t get up and get dressed and has a really hard time just even doing things like seeing something on the floor and picking it up. (P3, daughter of the person with depression)

Caregivers felt the person with depression was heavily dependent on them, and the sense of responsibility sometimes made the role overwhelming. The feeling was further compounded when the caregivers thought they were the sole social support of the person with depression.

He didn't like the separation. He is very clingy. I couldn't leave him for very long periods, if I had to do groceries or go to the drug store and pick up medications or anything, I have to keep calling him every fifteen minutes... I thought I was in a cell, I couldn't escape. (P2, wife of the person with depression)

Caregivers described feelings of interacting with a different person due to the manifestation of depression. Consequently, caregivers felt these depressive symptoms affected their relationship with the person with depression.

Family life. Caregivers reported adapting to the care provider role regardless of their familial relationship or previous dynamic, and they felt the need to take charge in most situations. Caregivers commented on spending more time with the person with depression due to caregiving responsibilities, but the interactions were more often related to instrumental support (e.g., driving to doctor's appointment) than leisure activities (e.g., playing board games). In addition, some caregivers revealed that families expressed disagreement about how to share caregiving responsibilities (e.g., taking the person with depression to doctor's appointments, spending time with the person with depression) and this increased family tension. As well, caregivers thought it was harder to communicate with the person with depression and had difficulties in getting the person with depression to openly share themselves. In general, caregivers felt that their relationship with the person with depression had been tilted off balance. They felt they were offering support and care without reciprocation from the person with depression, and some thought their own voices and feelings were not heard by the person with depression. These perceptions were accompanied by feelings of loneliness.

I think it's the feeling of being alone in it. You know? Like when you're the one looking after the bills, investments, and the future of this property, the family stuff, the kids... You kind of feel alone in it, because he is like "I don't care, don't tell me." Like I'm on the board of directors and he has no interest in what's happening and what I'm doing. (P10, wife of the person with depression)

In some cases, caregivers reported that the care recipient's illness brought the family closer together and they spent more time with each other. Although being a caregiver was difficult, these caregivers were thankful for the family becoming more connected.

"My Life Has Changed"

Caregivers reported changes in their lifestyle and well-being as they took on the caregiving role and responsibilities. Caregivers discussed experiencing symptoms similar to depression (e.g., low mood, anger), neglecting own health, and constantly worrying about the person with depression.

Caregiving responsibilities. Caregivers helped the person with depression with IADL and spent more time with them to ensure their well-being. Caregivers commonly reported driving the person with depression to places, accompanying them to doctor's appointments, navigating the healthcare system, doing household chores, paying bills, creating schedules for the person with depression to keep them active, and assuming responsibilities formerly held by the person with depression.

As well, caregivers reported being with the person with depression much more frequently, both in-person and remotely (e.g., telephone and FaceTime). They spent time with the person with depression when they had openings in their schedule and tried to alleviate the person with depression's depressive symptoms by keeping them active and accompanied. Many caregivers assumed the counselling role in these situations and

offered the person with depression encouragement to follow treatment plans and listened to the person with depression's concerns. During severe phases of depression, caregivers described the person with depression becoming completely paralyzed and unwilling to get out of bed. In these instances, caregivers helped them with ADL to ensure their wellness, including bathing, dressing, toileting and eating.

I go to the doctor with her. I can help her pay her bills. I had to sleep with her, get her up, take her to the bathroom. Living with her all day, cooking for everybody. And then we would go to her house and clean. (P1, daughter of the person with depression)

Lifestyle modification. Caregivers often modified their lifestyle to fulfill caregiving duties. Outside of caregiving, caregivers commonly reported multiple roles, requiring them to attend to employment, volunteer positions and other family members, and they experienced difficulties in accomplishing caregiving tasks in addition to their pre-existing responsibilities. Caregivers who were retired or had flexible work schedules planned their daily activities around the person with depression's needs. Since taking on the caregiving role, some caregivers worked fewer hours, took leaves of absence, or retired from their previous job to create time for caregiving activities.

I've taken most of the year off. I was her primary caregiver and she could not be alone, so I had to do everything for her... I would have to take a leave of absence from work because there would've been no one." (P1, daughter of the person with depression)

Some caregivers spent less time with other family members, but they recognized that other family members also required attention and ensured some time was reserved for them.

Just trying to find the time to balance my brother and my husband was demanding. I would say that all filters down into stress. (P9, sister of the person with depression)

In contrast, caregivers' social life and leisure activities were often neglected when they were busy. Besides not having time, caregivers also commented on being too exhausted to socialize. As well, some caregivers reported strong feelings of guilt when they socialized or spent time on their hobbies instead of with the person with depression. As a solution, some of them invited the person with depression to join their social functions or leisure activities.

It's no time and not only time, but socially I'm exhausted a lot of the times, so I don't really feel like hanging out. You get sucked into the vortex of this [caregiving] world, you just get caught in it. (P7, son of the person with depression)

When the person with depression was experiencing severe symptoms, caregivers made drastic changes to their life schedule and became fully involved. One participant described the situation as "all hands on deck" (P10, wife of the person with depression), and they put the rest of their life on hold and attended strictly to caregiving activities. The sudden onset of depressive episodes or the possibility of them deterred the caregivers from planning extended trips or time away from the person with depression.

When we're in crisis mode... my Christmas went out the window, and anything we have planned, like New Years, any events we have planned went out the window. It was all about taking care of my mother. (P1, daughter of the person with depression)

Well-being. Caregiver health was often negatively impacted by their caregiving role. Specifically, caregivers reported a decline in their mental and physical well-being, while their financial well-being was affected to a lesser degree.

Caregivers identified several psychological stressors since taking on the caregiving role. Constant worrying was noted as well as repetitive thoughts about the person with depression's safety, including self-destructive and suicidal behaviours, and their future, such as symptom deterioration. Caregivers experienced stress and exhaustion in these instances.

I'm worried about his state of mind, I'm worried about his health, I'm worried about whether he's going to pull through this. I'm worried about whether he's going to be okay... I think the worst part was just watching him go through that. Just having to watch. So a lot of time I would be at home worrying about how he was doing all day because I knew he was very unhappy and had nothing to do. (P9, sister of the person with depression)

Many caregivers revealed experiencing depressive feelings of their own in their caregiving role. Caregivers noted that their mood was heavily influenced by the person with depression's emotions, and their well-being felt dependent on the person with depression's condition. As well, the feeling of helplessness and inability to assist the person with depression further enhanced their depressive feelings.

Sometimes I come home and I just wanted to scream or cry. I have a lot of friends and wonderful kids, but in between I am really depressed. Thinking about it and trying to help [the person with depression]... Sometimes I wonder how much I am helping them because I'm dragging myself down. My well-being depends on how her mood is and how depressed she is. (P5, daughter of the person with depression)

Does depression breed? If you're looking after someone who's depressed, can you end up getting depressed? (P10, wife of the person with depression)

Frustration and resentment were also noted by several caregivers. These feelings arose when caregivers had to make undesirable changes to their lifestyle, and the feelings were further compounded when they did not feel appreciated for their efforts. Caregivers also described feelings of frustration when the person with depression was not following treatment plans.

I get very frustrated at her at times... I keep reminding myself that I have to do more for myself during the day or else it's not gonna happen and I start to feel resentful. I do feel frustrated when my mom feels like [my help] is not enough. (P3, daughter of the person with depression)

As well, caregivers commented on a decline in their physical health. Caregivers felt physically exhausted from helping the person with depression with IADL and not getting enough rest. Specifically, caregivers commonly reported doing household chores for the person with depression and driving them to places as tiresome activities. Additionally, caregivers did not attend to their own physical health, neglected exercising and rehabilitation, and they experienced physical discomforts or illnesses as a result.

I cut my [rehabilitation] short... I put my own health on the backburner and I shouldn't have done that. Because I have issues that I'm trying to deal with that had I taken steps a few months ago I wouldn't have the problems that I have right now. (P2, wife of the person with depression)

Caregiving did not have a large impact on the majority of caregivers' financial well-being. Most caregivers commented that their families were in good financial standing, and they were able to afford help when necessary (e.g., homemaking services). However, for caregivers who were financially dependent on their

employment, a reduction in working hours negatively impacted their financial well-being and led to stress. In addition, a few caregivers commented on not being able to perform at work due to constant worrying and exhaustion.

The hours I should be working are spent with my folks or dealing with those [caregiving] issues, then I'm not making money. (P7, son of the person with depression)

Stigma of Depression

Interviews suggested some of the people with depression, caregivers, and others in society expressed stigmatizing attitudes and behaviours about depression. Caregivers perceived disapproval, non-acceptance, or lack of empathy regarding depression, which hindered help-seeking efforts and reduced their social support. This increased the difficulties associated with providing care.

Stigma from the person with depression. Caregivers reported seeing the person with depression attributing their depressive symptoms as a weakness rather than an illness, and it delayed the person with depression from seeking treatment or asking caregivers for help. As well, caregivers thought the person with depression was worried about other people's judgment if they disclosed their mental illness, so the person with depression isolated themselves and hid their depressive symptoms from others.

We have lots of supports in our community, but she won't use them. You know, it [seems like] everything is great, and she wants to maintain that... there's so much stigma around mental health. You can't see a cast around it, so people stigmatize it, right? (P1, daughter of the person with depression)

Stigma from caregivers. Similarly, some caregivers attributed symptoms of depression, for example, lethargic behaviours and inactivity, as the person with depression's choice to be "difficult" and "lazy." As a result, caregivers felt frustrated and impatient when the person with depression refused to reach out for help or follow the treatment plan, and caregivers felt their empathy wane in these instances. The lack of understanding about depression discouraged caregivers from seeking support on the person with depression's behalf and diminished their motivation to help.

Her thing is "I got nobody, I'm all alone," she's not all alone. She's actually got a team of people around her. She's got all the resources she needs, both financial and otherwise. She acts like she's chained to the chair. No one is stopping her from taking a cooking class, or getting some exercise, or having a coffee with a friend or doing all this. She just refuses to. (P7, son of the person with depression)

Stigma from society. Caregivers also experienced a lack of understanding and acceptance of depression from members of their social network and society. Caregivers described interacting with people who wondered why the person with depression could not just get better or shake off the laziness, and they had to defend the person with depression and explain depression. As well, some caregivers witnessed people from their social network becoming distant, and they suspected the reasons being they did not know how to interact with the person with depression or were unwilling to be around someone with a low mood that was easily irritated. Caregivers thought society's negative perception of depression caused the person with depression to have less social support and become more reliant on their caregivers as a result.

One of our daughters sort of said at the time "well, why can't he just, you know, get his act together and come home?" ... Even my husband himself sort of said "you know, I ought to be able to just pull up my socks and get going and you know, I'm weak, not sick." (P11, wife of the person with depression)

DISCUSSION

Main Findings

The present study is the first to explore the experiences of caregivers to older adults with a formal depression diagnosis. Caregivers discussed adjusting to the person with depression's symptoms and the changes depression brought to their lives, in areas including family dynamics, lifestyle, and well-being. Findings highlight how stigma towards depression arises from the care recipient, caregiver, and society. In contrast to dementia caregiver research, our findings provide insight into the nuances associated with caregiving to older adults with depression. Specifically, although stigma towards individuals with mental illness is common in the literature, this is the first study to observe stigma in the older population. Additionally, caring for a person with depression is novel to many caregivers, and the study highlighted the unique experience of being constantly vigilant of the care recipient's safety and not knowing how to respond to their depressive symptoms. The authors propose the healthcare system should better prepare these caregivers by educating them about depressive symptoms management and involving them in the patient's treatment plan.

The findings of the present study expand upon studies examining caregiving to younger adults with depression, as this study highlighted the negative impact of caregiving on family members' psychological and physical well-being. Sewitch and colleagues' (2004) quantitative study suggested that caregivers of older adults with depression provided more care and had worse mental health and perceived quality of life compared to caregivers of non-depressed older adults. As well, qualitative studies on caregivers of younger adults reported that caring for a person with depression is both physically and mentally demanding as exhaustion (Ahlström et al., 2009; Hansen & Buus, 2013) and depressive feelings (Highet et al., 2004; Muscroft & Bowl, 2000; Nosek, 2008; Radfar et al., 2014; Skundberg-Kletthagen et al., 2014) were common. Consistent with previous research, a caregiver's constant vigilance for the person with depression's safety was emphasized. However, caregivers in our study highlighted the disabling effect of depression on their loved ones' ability to perform everyday activities. As a result, caregivers supported their person with depression's everyday activities and assumed extra household chores. In Priestley and McPherson's (2016) meta-synthesis, these caregiving roles were not frequently reported in caregivers of younger adults with depression. Caregivers in our study suggested household tasks were especially strenuous when caregivers had their own physical health concerns. When compared to existing research, this study illustrates the similarities between caregivers of older and younger adults, and it also highlights the additional responsibilities associated with caregiving to older adults with depression.

Stigmatizing attitudes toward depression exhibited by the caregivers, society, and people with depression themselves were observed in this study. Stigma is not common in other illnesses in older adults, such as cancer (Knapp et al., 2014), and brings distinct challenges to the person with depression and their caregivers. Caregivers interpreted their person with depression's inactivity as laziness rather than depressive symptoms, and this interpretation often led to frustration when providing assistance. Participants also alluded to the person with depression's own negative perception of depression and the unsupportive behaviours from society. This contributed to caregivers experiencing difficulties providing care and seeking support. This study also highlighted stigma's impact on familial relationships with the person with depression and their extended family members. Similar to schizophrenia (Bamgbade et al., 2016) and bipolar disorder (Cerit et al., 2012),

studies on depression have suggested that an individual's knowledge regarding the illness is essential to lowering internalized stigma (Bamgbade et al., 2016; Lu et al., 2016; Shann et al., 2019). For caregivers, both the World Health Organization (Hochman, 2007) and National Alliance on Mental Illness (E. C. Wong et al., 2016) indicated education as a key factor in reducing stigma. Offering education to caregivers about depression, methods to discuss depression with family and friends, and strategies to support the person with depression in managing depression can enhance their understanding of the illness, and potentially reduce their feelings of frustration and improve caregiver-recipient relationship (Lu et al., 2016; O. L. Wong et al., 2016).

Consistent with many caregiving studies, our participants experienced changes to their lifestyle, family relationships, and physical and mental well-being. Similar experiences have been observed in caregivers to individuals with dementia (Prince et al., 2007). Findings support the need for the healthcare system to adopt a family-centred model of care by involving the caregiving population in the patient's treatment plan. Recent studies about mental health treatment suggested including the patient's family members in their treatment plans (e.g., regular meetings with caregivers to follow-up with care recipient's progress, educating caregivers about mental illness) may be the best practice for supporting the well-being of both the individual with mental illness and their family (MacFarlane, 2011; McNeil, 2013). Specifically, family-centred care in outpatient psychiatry has been associated with improvements in caregiver and patient outcomes (e.g., less caregiver burden, improvements in patients and caregiver health; Heru, 2015). By including families in the patient's treatment plan, they can assist patients with appointment attendance, medication adherence, and emotional support. As well, families become more knowledgeable about care recipient's illness and understand ways they can support the care recipient, thus reducing their own caregiving stress. Policymakers who aim to implement family-centred care for older adults with depression may consider resolving the challenges (e.g., billing structure, training for family-centred care) that clinicians and organizations encountered when trying to apply similar changes in other illness populations (Leonard et al., 2018; O. L. Wong et al., 2016).

The study suggests future research needs to explore the experiences of caregivers to older adults with depression and other conditions. The current study aimed to explore the experiences of caregivers of older adults who had depression as their primary reason for care, but all the care recipients in this study had other age-related health conditions. To continue to understand the interplay between depression and other age-related illnesses, future research can examine caregiving to populations that commonly have depression as a comorbidity. Depression is commonly associated with several age-related illnesses, such as hearing (Li et al., 2014) and visual impairment (Eramudugolla et al., 2013), stroke (Robinson & Jorge, 2016), cancer (Krebber et al., 2014), and dementia (Goodarzi et al., 2017). As well, some depressive symptoms can be more prominent in the presence of comorbid illness. For example, suicidal ideation is commonly associated with post-traumatic stress disorder (O. I. Gonzalez et al., 2016) and low mood and irritation are common in patients with chronic pain (Fitzgibbon et al., 2016). Caring for a person with a serious illness and depression can be complex, and future research can build on the current study by understanding caregivers' experiences and support needs.

LIMITATIONS AND CONCLUSION

There were some limitations regarding the demographic diversity of participants. Firstly, due to the sample size, the interviews of all participants were analyzed together regardless of caregiver and care recipient's familial relationship. This limited the current study's ability to examine similarities or differences in caregiving associated with the familial role. As well, most participants in the present study were women, limiting our ability to explore any gender comparisons. Another limitation of the study may result from the high income and high educational level of our study population. Many participants were able to afford additional homemaking and/or respite care services, and the perspectives of caregivers who experience financial struggles may be absent from the study findings. Future research may examine the impact of caregivers' demographic characteristics and familial relationship on the caregiving experience to persons with depression.

This study contributes to our understanding that an older adult's depression has a profound effect on their family caregivers, as they are at risk of developing their own health concerns. The findings emphasized the need for a formal and structured approach to help families, as caregivers were often responsible for supporting older adults' unmet needs. Additional resources from the healthcare system may be a key element in reducing the psychological and physical stress that caregivers experience. This study provides insight into caregiving to older adults with depression and highlights the impact caregiving can have on caregivers' health and well-being and their need for a significant level of education and support.

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