

Caring for the Caregiver



A study on the experiences of family caregivers of persons living with mental illness or addiction

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HÔTEL-DIEU
ESTE GRACE
HEALTHCARE



University
of Windsor

we*x
spark

It all started with the Hôtel-Dieu Grace Healthcare (HDGH) Patient & Family Advisory Council...

- Advisory group who share perspectives, offer advice, provide input on MH&A care provided at HDGH
- **Members have first-hand knowledge of the significant – critical – role of the caregiver in supporting the well-being of those living with mental illness and addiction challenges...**

But who supports the caregiver?





The impact of caregiving on the caregiver

Caregivers of loved ones living with mental illness and addiction face **different and unique challenges** compared to other caregivers of long-term conditions:

- Day-to-day stress related to unpredictability of the illness^{1,2}
- Complexity of illness can make it difficult to manage and treat³
- Stigma associated with mental illness and addiction⁴
- Isolation and/or lack of social support⁵

¹Schulze, B. & Rössler, W. (2005). Caregiver burden in mental illness: Review of measurement, findings and interventions in 2004–2005. *Current Opinion in Psychiatry*, 18, 684–691. ²van Wijngaarden, B., Schene, A., & Koeter, M. (2004). Family caregiving in depression. ³Lindt, N., van Berkel, J., & Mulder, B. C. (2020). Determinants of overburdening among informal carers: a systematic review. *BMC geriatrics*, 20(1), 304. ⁴Flyckt, L., Fatouros-Bergman, H., & Koernig, T. (2015). Determinants of subjective and objective burden of informal caregiving of patients with psychotic disorders. *The International journal of social psychiatry*, 61(7), 684–692. ⁵Corrigan, P.W., & Wassel, A. (2008). Understanding and influencing the stigma of mental illness. *Journal of Psychosocial Nursing*, 46, 42-48.

“ Providing care and support to someone with a mental illness can be a daunting task. The often unpredictable and lengthy course of mental illness is compounded by stigma and by historical barriers to family involvement in the mental health system... [Without adequate support] families are left to fend for themselves as they try to help their loved ones recover from mental illness and, at the same time, keep themselves afloat

”
- Ella Amir

- Chair, Family Caregivers Advisory Committee, Mental Health Commission of Canada

A ‘grassroots’ effort to support caregivers

The Advisory Council recognized the urgent need and proposed a “Caring for the Caregiver conference”, with the following goals:

- **Providing relevant education**
- **Promoting caregiver well-being**
- **Supporting connections among local caregivers**

How do we make the conference meaningful? **Listen to people with lived experience.**





Caring for the Caregiver Study

Research partnership between HDGH, the University of Windsor, and WE-SPARK Health Institute

Study Purpose: To identify and describe the unique experiences and the support needs of caregivers residing in Windsor-Essex County*

* Caregiver = defined as an “informal” and/or “unpaid” family member or friend support person of an adult living with mental illness or addiction⁶

⁶Happell B., Wilson K., Platania-Phung C., & Stanton R. (2017). Filling the gaps and finding our way: family carers navigating the healthcare system to access physical health services for the people they care for. *Journal of Clinical Nursing*, 26, 1917–1926.

Study Methodology

Two strategies used to engage local caregivers in the study (“Mixed methods”):

1. Community-wide survey

(Jan 2021-April 2021; N=78)

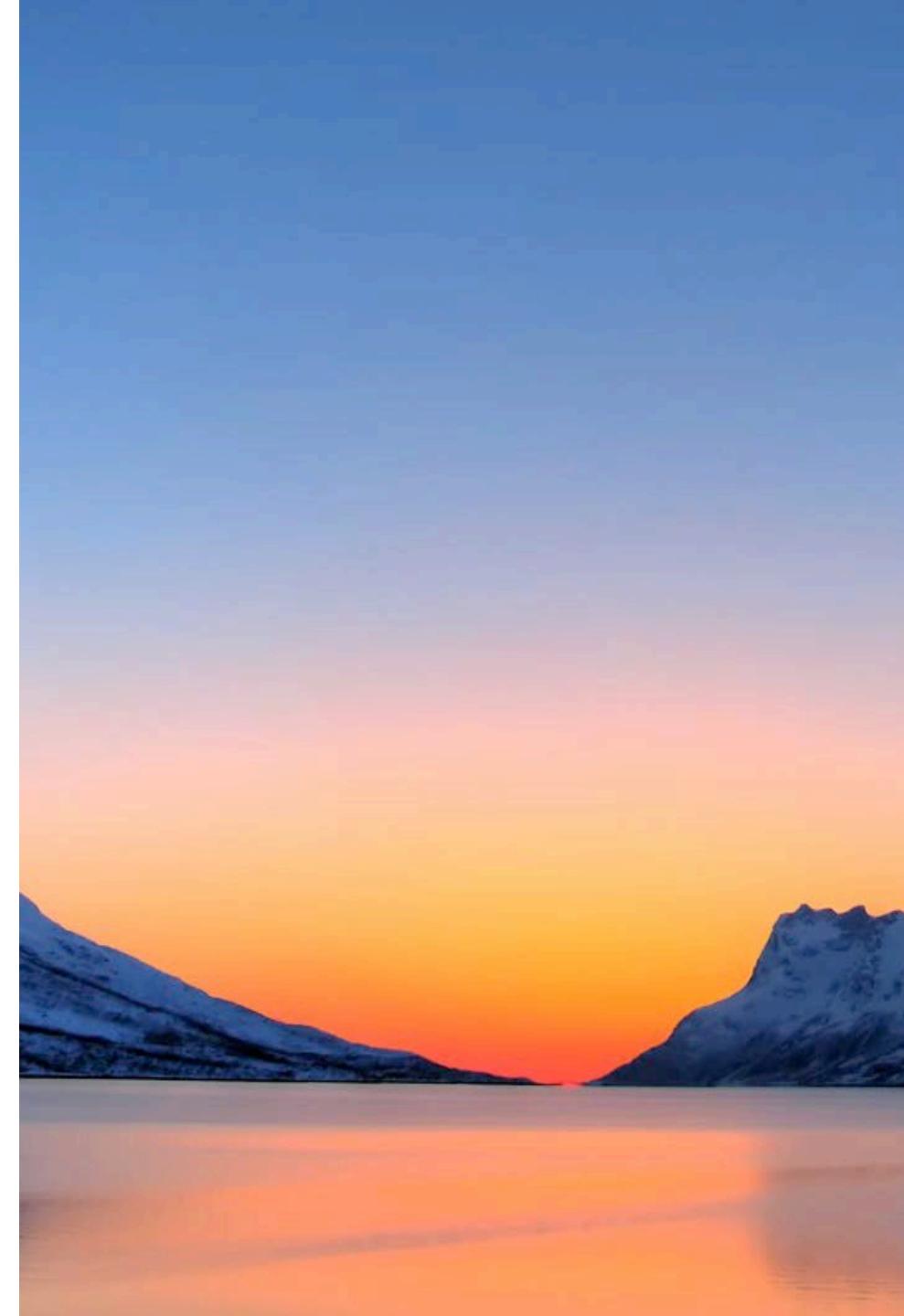
- Demographic information
- General Health of Caregiver Survey (*RAND Healthcare, 2020*)
- Burden Assessment Scale (*Dare et al., 2008; Reinhard et al., 1994*)

2. One-on-one, in-depth interviews

(Feb. 2021 – June 2021; N=21)

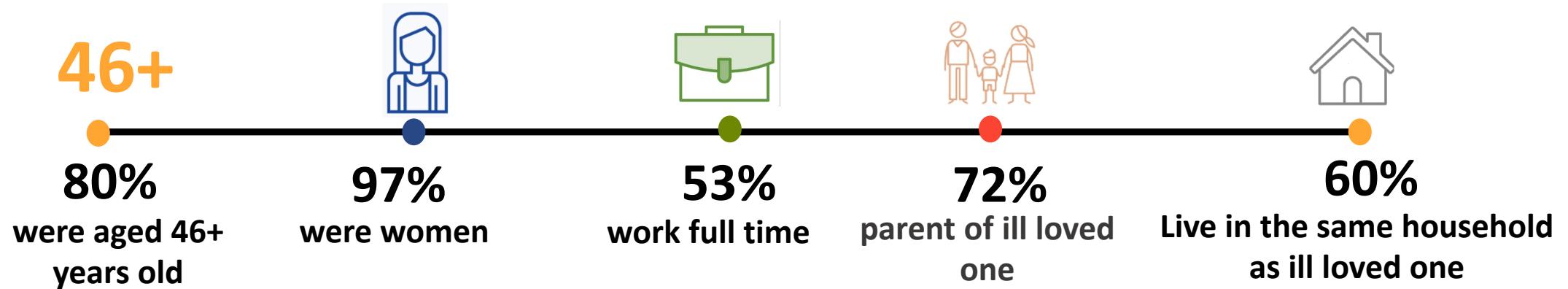
- Deeper dive into the challenges and rewards of caregiving, coping strategies, and caregiver support needs

“Research into Action”: All data gathered informed the Caring for the Caregiver conference program and session content



What did we learn? A snapshot of survey results.

By the Numbers: A closer look at demographic and clinical characteristics of our 78 caregiver participants and their loved ones



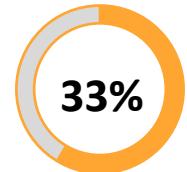
Mental illness and/or addiction diagnosis of loved one:



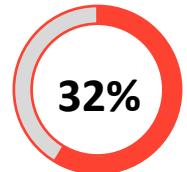
Anxiety



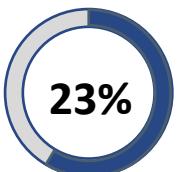
Depression



Addiction



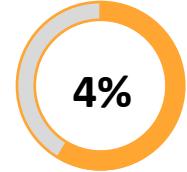
Bipolar



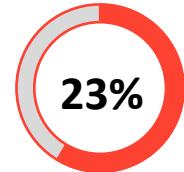
Schizophrenia



Personality
Disorder



Eating
Disorder



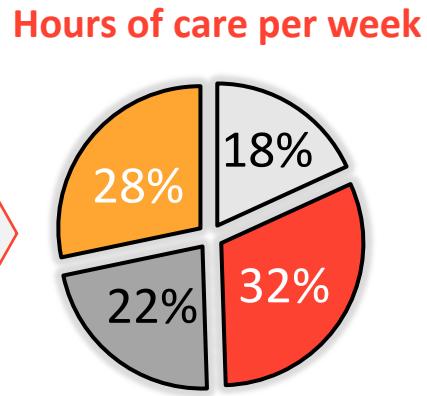
Other

Overall, 77% of participants are caring for a loved one living with multiple conditions

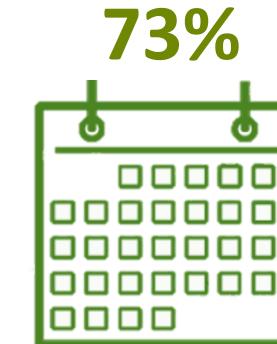
What did we learn? A snapshot of survey results.

By the Numbers: A closer look at the involvement and impact of caregiving on our 78 participants

Almost 1/3 are devoting 5-10 hours per week providing care for their loved one

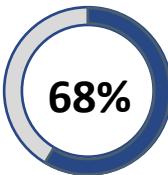


- Less than 5
- 5 to 10
- 10 to 20
- More than 20



Majority of respondents are providing long-term support to their loved one

In the past 4 weeks, caregivers reported:



Cutting down on the amount of time spent on work or other important activities



Accomplishing less than they would have liked



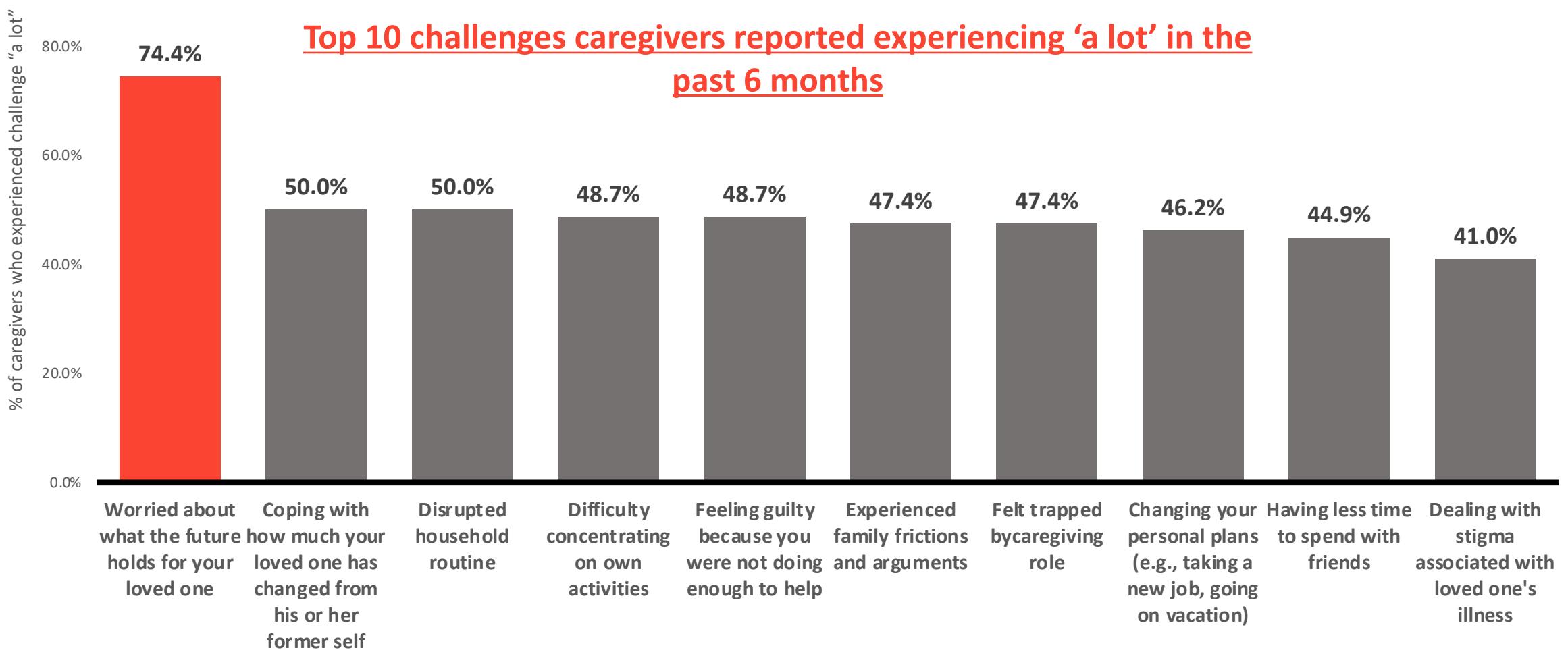
Not completing work or other important activities as carefully as usual



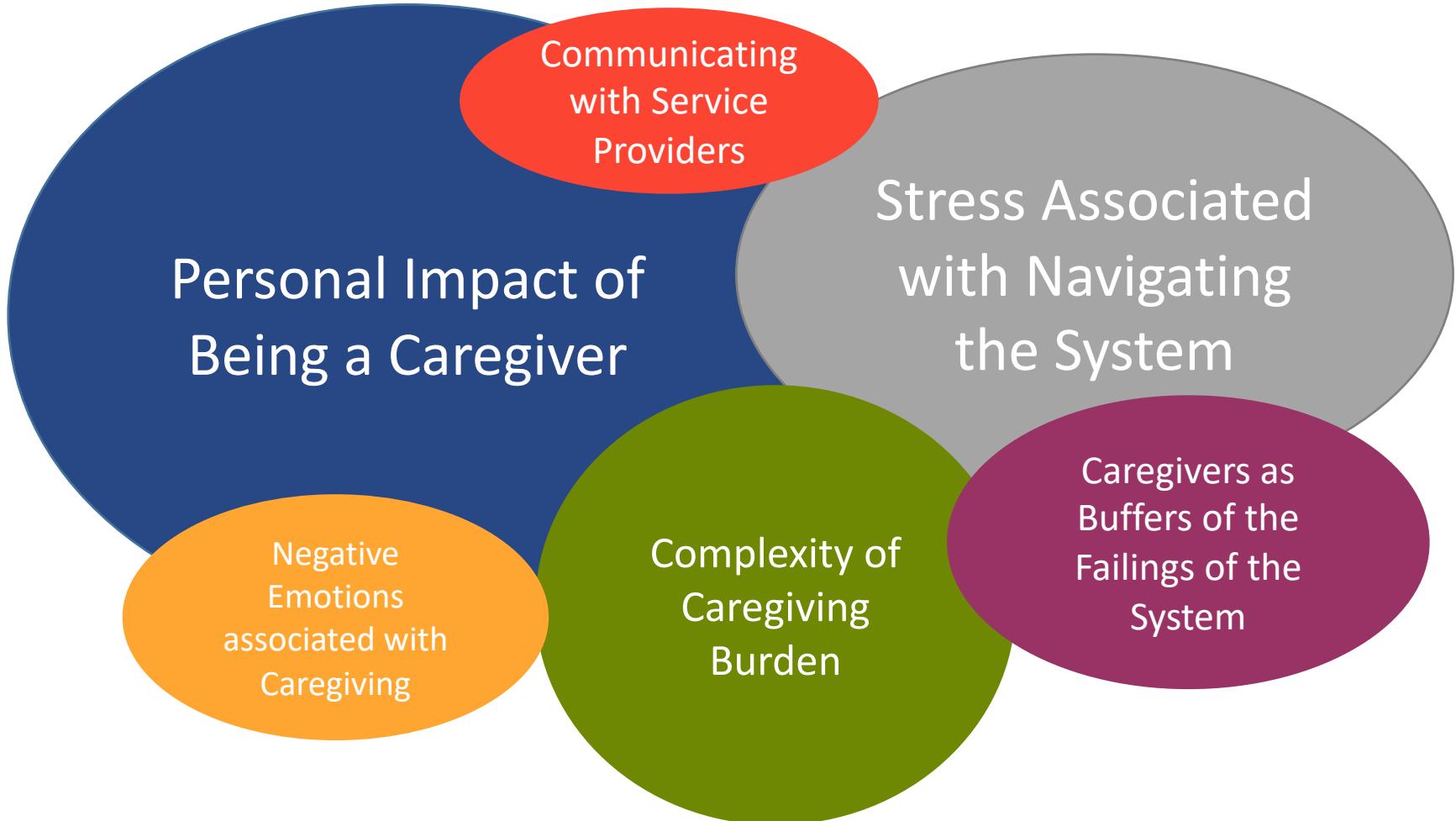
Stress interfering with normal social activities with friends and family

What did we learn? A snapshot of survey results.

By the Numbers: A closer look at the challenges associated with caring for a loved one living with mental illness or addiction



What did we learn? Themes from the interviews.



Theme 1: Personal Impact of Being a Caregiver

Participant 002 - [my loved one] doesn't have children, I don't have any kids, and as we're growing older ...I find, the difficulty of caring for her until she, you know, she's in her golden years, and at the same time I'm also looking forward retiring and it seems like I'm retiring to assist her and being with her... and so that's a challenge for me at the moment.

Participant 007 - I'm not a social worker, you know, and I just, I get a little tired. You know, like, who else will pick up my [loved one] and take him to this thing, and bring him home? You see, it's almost an impossible thing, isn't it? Nobody else is going to pickup [my loved one] and take him for groceries, make sure he's got enough food.

Theme 1: Personal Impact of Being a Caregiver

Participant 017 - [Loved one's] symptoms sometimes come out as anger, um, which is hard for me, like, you know, if I get home from like a tough day at work and [loved one]'s not doing well, ...it's like I don't have my 'me' time.

Participant 020 - I have my own health challenges that complicate things, so I work through the mud of my stuff while looking after people. My person has become much higher functioning in terms of self-care, able to make meals for themselves, able to self-monitor a lot of, you know, to watch out for their triggers, watch out for their red flags, sort of keep on top of their own situation. So we have a joke that my helicopter has landed. I'm know longer circling and helicoptering, I'm just on the ground with the motor running for when, if and when I need to, lift off again.

Theme 1: Personal Impact of Being a Caregiver

Participant 005 - This has been a financial drain that we definitely didn't plan when he took that early retirement. It's likely contributing to me still working as well.

Participant 017 -And I'm just thinking about the future, like, yeah, like not being able to ever afford our own place is always stressful. It's definitely taking a toll on me.

Theme 2: Stress of navigating the system

Participant 001 - If we're driving ourselves crazy trying to find care for the person we are providing care to, there is no help for us. All the work that we do is for nothing because we can't help them by ourselves. We can't prescribe medications, we can only help when there's a crisis, to the limits of our abilities...

Participant 012: I will say, we did bring him into the hospital in crisis and that's a joke. The hospital is a big, fat joke. Um, they, you know, I'm sure you've heard this before from other people but, like, if he presented with a broken arm, they would not say to him, sorry come back in 6 months and we'll set your arm, but when people are suffering from mental illness, they say...they don't keep you and they send you away and they give you suggestions for programs, but the wait list is 6 to 8 months, um, and how does that help a person?

Theme 2: Stress of navigating the system

Participant 009: I'm retired, have no access to health care services or counselling so [my loved one's illness] became an issue again this year. I feel helpless and lost and it, um, called the family doc and the family doc wouldn't give him any meds and it just, it just goes downhill from there.

Participant 020 - I did have a social worker on the team who was... very, very good about providing support and I relied a lot on her expertise as for as, "oh, this is something many people go through, oh that's a normal symptom, oh it does take two to three years, oh two years since you got off drugs, oh, o.k. I can sleep now". Um, so it's good to have that for touchstone and reality check. I think it was good for them to know that they have a team that they could count on. Nobody ever said we're gonna make you better, we're gonna fix you, um, that weren't any ----- ridiculous expectations in that regard.

Theme 2: Stress of navigating the system

Participant 003 - It took us a year to get support from [name of organization] - a year - so often these people leave the hospital and are left on their own and they circle back around. I've asked for him to be put into [name of organization], there's a program in [name of organization] there's a [type] program ...but the only way you can get ...the counselling or long-term program, is if you are re-admitted into hospital, which doesn't make sense to me. My [loved one] had many suicide attempts and hospitalizations. Why is [my loved one] not a candidate for that? Why does he have to be re-admitted into hospital to have access to that? I don't understand the way things are functioning. Like, now he's in the XXX program with [name] but it's not effective, it's not. Especially now, he's sitting at home, the nurse doesn't come to house anymore, she phone calls. What's a phone gonna do? Nothing! I don't understand, while they're in the hospital, they get stable, that's the time they should be given extra support, the extra counselling, the group, not released into the community so they can circle back around. So there's a gap, a big gap missing here as far as getting appropriate help for them I guess and ... it falls back on the caregivers... So, it's just my feeling about it, it's very frustrating.

Theme 3: Complexity of Caregiving Burden

Participant 019 - I have in the past [thought about giving up my caregiving role] and then it's like he'll get arrested and well he's in jail and he's off the drugs so he comes back to normal and then he gets out he's usually it seems to be 9 days, that's the magic number within 9 days he's gone again. So, when as soon as he's gone, that's it I'm done, I'm not gonna help him no more, I can't deal with this and then he ends up getting picked up by the police, spends a couple months in jail and we're back to square one. It's like I feel like I'm the only person that he has...I feel like, if I don't help him, he's out on the streets.

Participant 020 - My family had difficulties with the police in the past and I'm aware of what they're capable of when they're confronted with violence. Anything can happen. So to try and minimize the stigma, um, because it does hit, like, a pathogen from the air that [you] didn't see, you know, it just lands on you. So, yeah another [crisis] would, please God, no.

Theme 3: Complexity of Caregiving Burden

Participant 017 - If I wasn't there to, like, pitch in, then I honestly think he might end up on the street, like, I really have no idea what would happen to him. ...and then I feel super guilty about that and it's just that negative thought pattern of like, what if, what if, what if? Um so that's been like a huge source of stress for me.

Participant 002 - I also help out to take care of [another family member] so that as well some days when, well now my [loved one] lives with me, but there are days during the week when I actually have to leave my [loved one] here, alone, to take care of my [other family member] because they [also require ongoing care] and so also needs attention and before it used to be the... nurses used to come and [help] clean her up, assist her with dinners and you know, just keeping company and because of the pandemic they don't come so now it's [me and my other siblings] who go to help her out. Now I have both of them.

Theme 4: Caregivers as Buffers of the failings of the system

Participant 003 - There is nothing on weekends. Mental health does not stop at 5 o'clock pm and restart the next morning. It doesn't stop on a Friday evening and restart on Mondays. Like I don't understand how they expect families to deal with all this when there's nothing available on evenings or weekends. That's a big challenge for me and I'm sure I'm not the only one

Participant 001 - As long as it takes, as long as I live, that'll be our role.

Theme 5: Communicating with service providers

Participant 015 - I think as a caregiver it's so important to be in the loop... however, I know there's the Mental Health Act, rights with privacy and ----- - but maybe that could, maybe that should be changed (chuckles). So yeah just communication with the caregiver has to be almost as important, I would think, as the communication with the patient because the patient isn't exactly in the right state of mind, right.... I think at the beginning stages more emphasis on the caregiver's role and how they can actually help their loved one cause when I would help, when my [loved one] came home from the hospital, I was relying on my own education and I was coming up with plans for how to care for him and that was, that was like pretty daunting.

Theme 5: Communicating with service providers

Participant 009 - Like the family doctor just kinda said to us, oh you know, oh well, you know. No attention to that detail is what's concerning for me. And it is, we've been bounced around because we're older, so the family doctor that I trusted for whatever, 50 years has retired of course, like me and we've had to move to three different family doctors in the last couple of years, so there's that lack of continuity of care.

Theme 6: Negative emotions associated with caregiving

Participant 010 - ...Devastated is probably the best way or a bit of a relief because ...because for the most part you run across empathetic people but you'd also come across those people that would look at you like, why can't you control this child? And so there was always... work was never, um, free of the burden of being a parent because I interact with so many people and there was a special care teams that would come into [the] classroom, I had also dealt with them so everybody knew all this, it was all very public. So there's a bit of... embarrassment isn't the right word but it's similar to that and you feel you should be able to help...and when you can't help your own child, it's pretty devastating...

Theme 6: Negative emotions associated with caregiving

Participant 011: When my [loved one is] depressed, I feel lonely because he's not getting out of bed and when he's in his mania mode, he's like busy, busy, busy trying to catch up with everything so then I feel lonely again because he's busy being busy, you know (chuckles) and being good but you're happy to see they're out and doing things but then you're like, hello over here so, yeah.

Theme 6: Negative emotions associated with caregiving

Participant 017: At times... I feel really guilty but I wonder, if I had met someone else, what would my life be like? Um, I sometimes feel, like, a bit trapped because I think like if I left, who would take care of [my loved one]?

Conclusions

- Caregiving is an on-going, isolating role.
- **Caregivers' experiences of caregiving are closely related to their ill-family members' experiences of the illness.**
- Caregivers require support navigating the system for their loved one.
- Caregivers also require support for themselves.

Invitation: Study Phase 2:

- All family caregivers who will attend the Caring for the Caregiver Conference will be invited to complete an online survey about their satisfaction with the event.
- Participants who provided their email address during the conference registration will receive an email following the conference with a link to complete the online survey
- We will also be inviting about 10-15 participants for a brief interview to hear about your experiences with the conference.
- These results will inform future Caring for the Caregiver events.

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