



INFORMAL CAREGIVERS, EXHAUSTED AND IMPOVERISHED BY THE PANDEMIC.

RESULTS OF A SURVEY CONDUCTED BY THE
REGROUPEMENT DES AIDANTS
NATURELS DU QUÉBEC - JULY 2020

In recent months, informal caregivers have experienced exceptional situations associated with the COVID-19 pandemic.

The Regroupement des Aidants Naturels du Québec (RANQ) is interested in the consequences of the pandemic on informal caregivers in order to better support them in the upcoming months and to raise awareness among the population and policy-makers about the challenges they are experiencing during the pandemic and on a daily basis.

Participants were informal caregivers recruited through our member groups or partner organizations and through social media (e.g. Facebook, Twitter). Thus, it is important to take into account that the informal caregivers responding to this survey recognize themselves in the caregiving role they play, which could explain why they have more support than others who do not recognize themselves as such.

The survey addressed the following parts: the physical and emotional consequences for informal caregivers, their need for support, balancing work and caregiving responsibilities, impoverishment and fears of a second wave.

We received 437 responses in 11 days, 84% of which identified themselves as women.

PROFILE OF INFORMAL CAREGIVERS

Of the informal caregivers who responded, 58% are informal caregivers to seniors (seniors' IC), 33% are informal caregivers to adults that are sick or that have a disability (adults' IC), and 9% are informal caregivers to minors who are sick or have a disability (childrens' IC).

12% of the respondents fulfill the role of an informal caregiver for at least two people.

We note that 60% are informal caregivers for a person living in the informal caregivers' home, 29% for a person living in accommodation, and 26% for a person living in their own home. The child ICs that participated in the survey all live with the child concerned.

Figure 1 : Distribution of ICs According to the Age Group of the Person They Care For

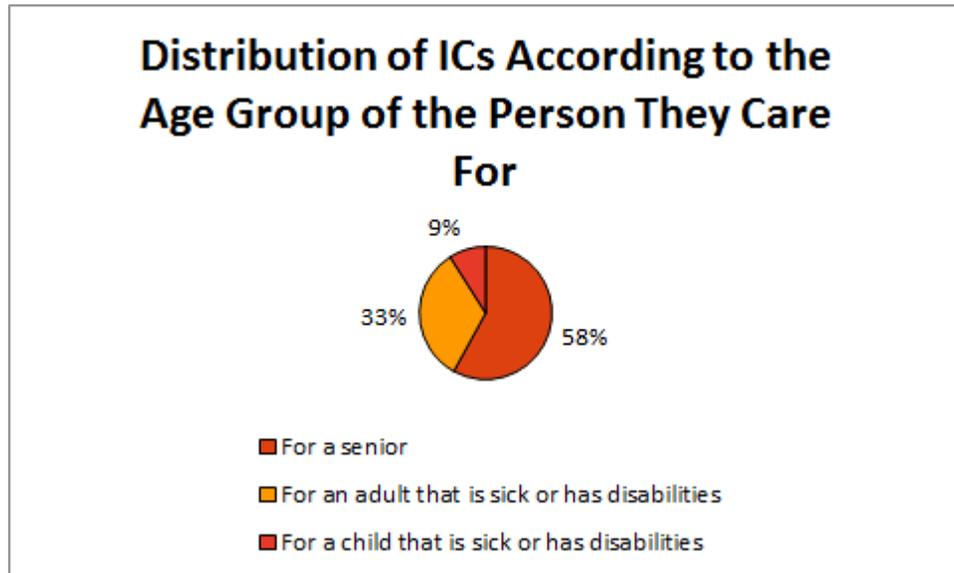
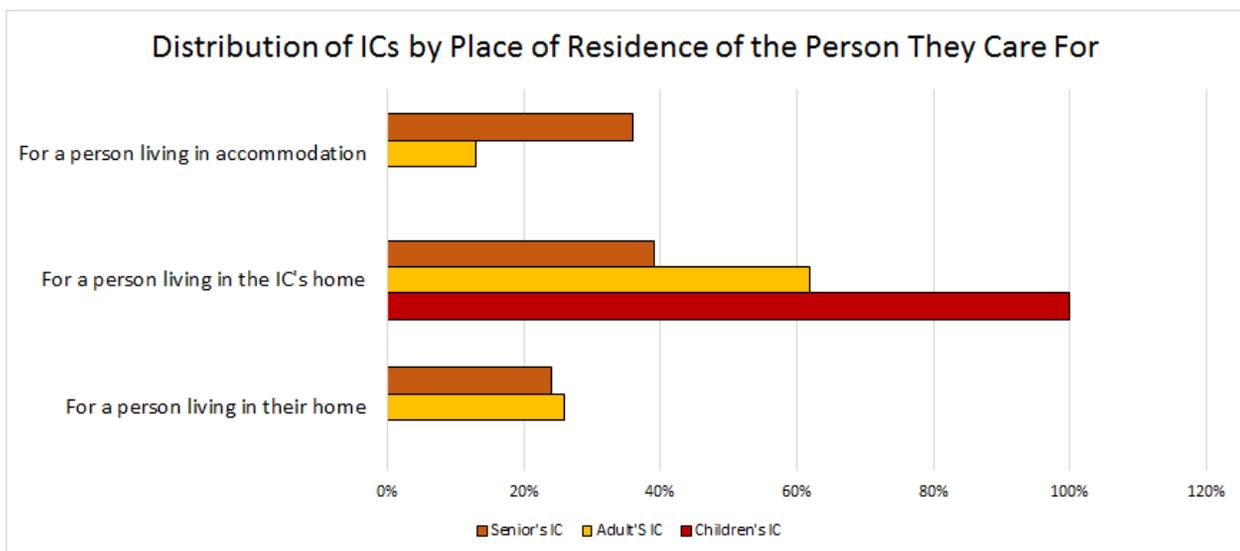


Figure 2 : Distribution of ICs by Place of Residence of the Person They Care For



PHYSICAL AND MENTAL CONSEQUENCES OF THE PANDEMIC

Since the beginning of confinement, we have observed that about a third of informal caregivers no longer have enough time for themselves, are torn between their various responsibilities and feel isolated from their family or friends. Also, around 40% of them sometimes lack patience towards the person they care for, or feel that they will not be able to take care of them for much longer.

Table 1 : The Burden of the Informal Caregivers' Role¹

	Never	Rarely	Sometimes	Quite often	Most of the time
Felt like you weren't doing enough for the person for whom you are an informal caregiver	19 %	20 %	30 %	22 %	11 %
Felt that because of the time spent with the person for whom you care for you didn't have enough time for yourself	12 %	10 %	28 %	34 %	16 %
Felt torn between caring for whom you are an informal caregiver and your other family or work responsibilities	14 %	16 %	25 %	29 %	16 %
Felt that you don't have enough money to take care of the person for whom you are an informal caregiver	43 %	20 %	14 %	9 %	14 %
Felt that you lack patience with the person you are taking care of	14 %	20 %	40 %	21 %	5 %
Felt that you won't be able to take care of the person for whom you are an informal caregiver for much longer	23 %	18 %	38 %	16 %	5 %
Felt like you've lost control over your life	21 %	16 %	30 %	23 %	10 %
Wished you could leave the care of the person for whom you are an informal caregiver to someone else	26 %	23 %	31 %	16 %	5 %
Felt that caring for the person for whom you are an informal caregiver is a burden, a load	18 %	20 %	36 %	21 %	6 %
Felt isolated from you family or friends	13 %	13 %	30 %	30 %	14 %

*Percentages are rounded to the nearest whole number. Thus, the total of the %s for a row is approximately 100%.

More of those supporting a minor than those supporting an adult or senior felt that they did not have enough money to look after the person they care for. Also, they often felt torn between balancing work, family and caregiving, and felt that they were losing control of their lives.

¹ See Appendix A for illustration of significant responses.

Informal Caregivers in the Context of a Pandemic

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Needs of Informal Caregivers



Physical Exhaustion

29% of informal caregivers no longer feel very fit and have less and less energy.



Mental Exhaustion

25% of informal caregivers say that they are rather sad and irritable, that they no longer want to take care of themselves and that they feel overwhelmed.

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Physically, at the time of the survey, 35% of ICs felt that they had energy and were quite fit, but had to give up many activities and projects. On the other hand, 29% of the ICs associated themselves to the following answer: "I'm not in great shape anymore and I have less and less energy. I often feel like sleeping. Every activity requires a lot of effort from me. »

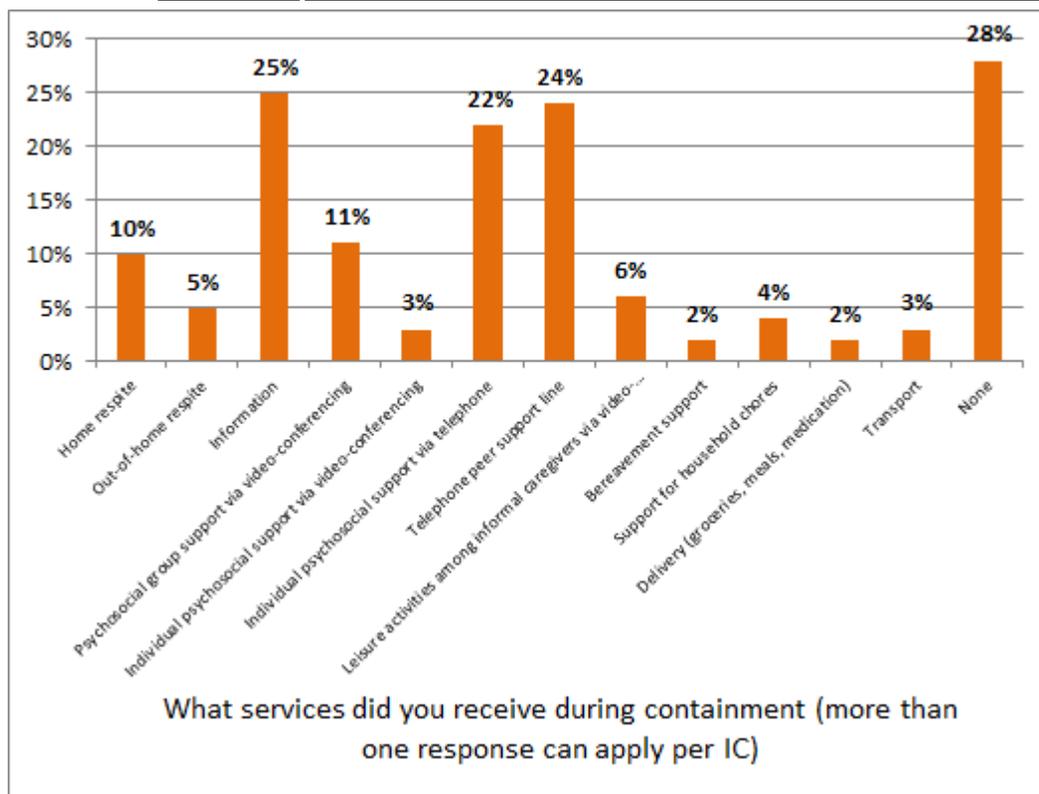
Emotionally, at the time of the survey, about 1/3 of ICs say they are usually in a good mood, taking life in a good way and not worrying about it. Still, one-quarter of the IC respondents say they are sometimes cheerful, sometimes sad, often irritated, not sure where at what point they are and that it is getting harder and harder to get back on their feet.

PANDEMIC SUPPORT NEEDS

94% of responding informal caregivers (IC) already considered themselves to be ICs prior to the pandemic. Of these, 86% benefited from a support system prior to the pandemic: from the CLSC (39%), a community organization (29%), an ESSAD (1%) or a private company (4%). The most accessible support services during the confinement period were access to information, telephone peer support lines, and individual psychosocial support by telephone.

At the time of confinement, 28% of responding ICs did not benefit from a support system.

Figure 3 : Services From Which ICs Benefited During Confinement



In addition, the services that ICs would have needed most during confinement were support with household chores for 22% of respondent ICs, in-home respite for 18%, and out-of-home respite for 16%, followed by individual psychosocial support by telephone for 15% of respondent ICs.

As deconfinement gradually takes hold, the services that would best support informal caregivers in this post-crisis context are individual psychosocial support, support with household chores, coffee clubs, in-home respite and out-of-home respite.

Table 2 : Support Needs of ICs in the Context of Deconfinement

As deconfinement is gradually being put in place, what are the 3 services that would best support you in this post-crisis context?	Support Services	Proportion of <u>Seniors' ICs</u> wishing to benefit from this support service	Proportion of <u>Adults' ICs</u> wishing to benefit from this support service	Proportion of <u>Childs' ICs</u> wishing to benefit from this support service
	Support for household chores	29 %	27 %	59 %
	Home respite	28 %	24 %	50 %
	Out-of-home respite	24 %	21 %	41 %
	Individual psychosocial support	24 %	20 %	32 %
	Night respite	23 %	19 %	18 %
	Delivery (groceries, meals, medication)	20 %	13 %	15 %
	Respite home (respite accommodations)	20 %	12 %	12 %
	'Coffee Clubs'	17 %	11 %	12 %
	Leisure activities among informal caregivers	9 %	9 %	12 %
	Information	9 %	9 %	3 %
	Transport	5 %	5 %	3 %
	Group psychosocial support	3 %	2 %	0 %
Bereavement support	2 %	2 %	0 %	

*Here, the total is not 100 %, since respondents could make up to 3 choices.

At the time of the survey, only 3% of responding ICs had to grieve the death of the person they were caring for, whether it was the death from COVID-19 or for any other reason. For this bereavement, ICs received support from informal caregiver organizations (45%), the helpline Deuil (18%), specialized bereavement organizations (9%) or a psychologist or health professional from the private sector (9%).

WORK AND FINANCES IN THE CONTEXT OF A PANDEMIC

BALANCING WORK AND CAREGIVING RESPONSIBILITIES

Informal Caregivers in the Context of a Pandemic

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Work and Finances



Increase of Expenses

20% of informal caregivers saw their expenses related to their role increase by an average of \$890.

Impoverishment

64% of informal caregivers did not receive any financial assistance from the CERB, the Compassionate Care Benefit or unemployment insurance.

57% of informal caregivers occasionally felt that they lacked the financial resources to care for the person they look after.



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27% of surveyed ICs were working before the pandemic: more child's ICs were working (47%) before the pandemic. Senior ICs who were working before the pandemic (21%) were more likely (43%) to have had to balance caregiving responsibilities and work during the confinement, and thus had to balance caregiving and telework.

In addition, 25% of ICs stopped working during the lockdown because their company closed or their job type did not allow them to telework. Among these ICs, the estimated loss of income is about \$3,000; half of these ICs had an estimated loss of income above \$2,000.

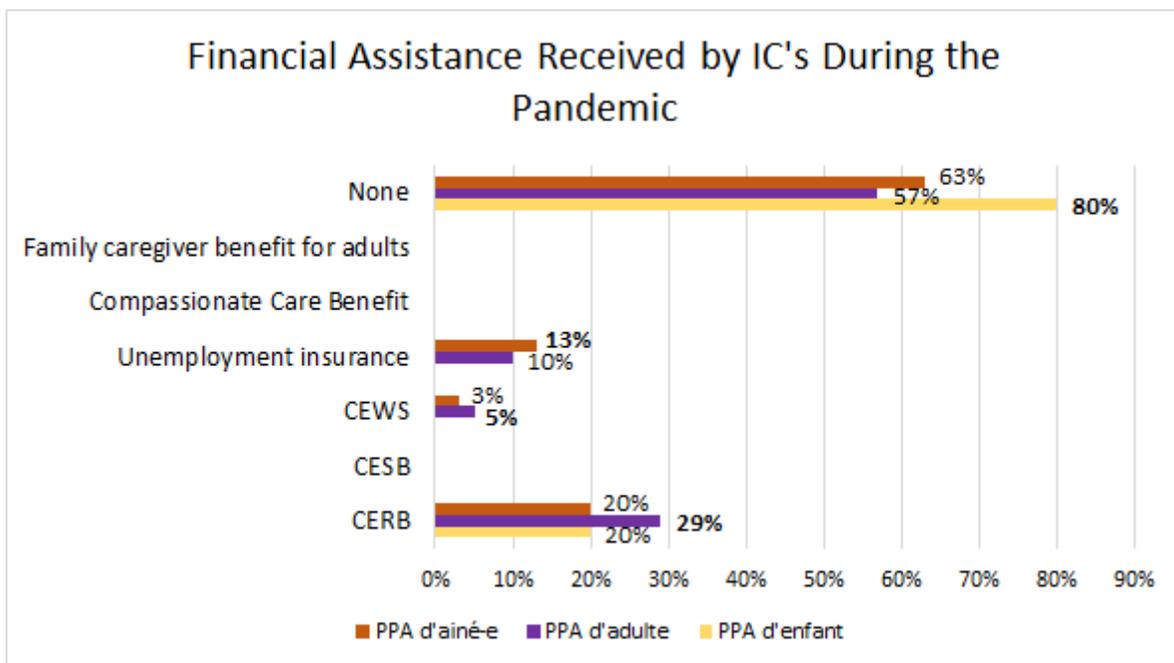
At the beginning of July, 31% of informal caregivers who did not work during the confinement did not return to work following the deconfinement for fear of infecting the person they care for, and 22% of them did not return to work

because they did not have a respite or care system for this person, for example because of the closure of day care-aid centers. Child's ICs have more barriers to returning to work than others, followed by adult ICs and senior ICs.

Surprisingly, only 17% of the senior ICs did not return to work for fear of infecting the person they care for, compared to 50% of the adult and child ICs, even though seniors are at greater risk of falling ill. This may be because seniors live more in accommodations than in their own homes or in the home of the IC and therefore contact may be reduced or not necessary.

Of the responding ICs, 64% did not receive financial assistance from any of the following: the CERB, the CESB, the CEWS, unemployment insurance, the Compassionate Care Benefit, the Family caregiver benefit for adults. 80% of child's ICs had no assistance at all.

Figure 4 : Financial Assistance Received by ICs During the Pandemic



HIGHER ROLE-RELATED EXPENSES

During confinement, 20% of the responding ICs experienced an increase in their expenses related to their caregiving role. Indeed, they estimated that the average additional expenses were \$890, sometimes as much as \$6,000 in additional expenses. It should be noted that fewer of the senior ICs reported an increase in expenses (19%), while one-third of the adult and child ICs reported an increase.

On the other hand, just under half of the ICs feel that expenses related to their caregiving role have remained stable.

FEAR OF THE SECOND WAVE

With the possibility of a second wave of the pandemic in mind, the two biggest concerns of the ICs are specifically related to coronavirus disease. Having a person cared for that is sick represents 57% of the fears, and getting sick themselves represents 49% of the ICs fears.

Unsurprisingly, older ICs are more concerned than other ICs that the person they care for will get sick, but child's ICs see all fears being exacerbated.

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Second Wave



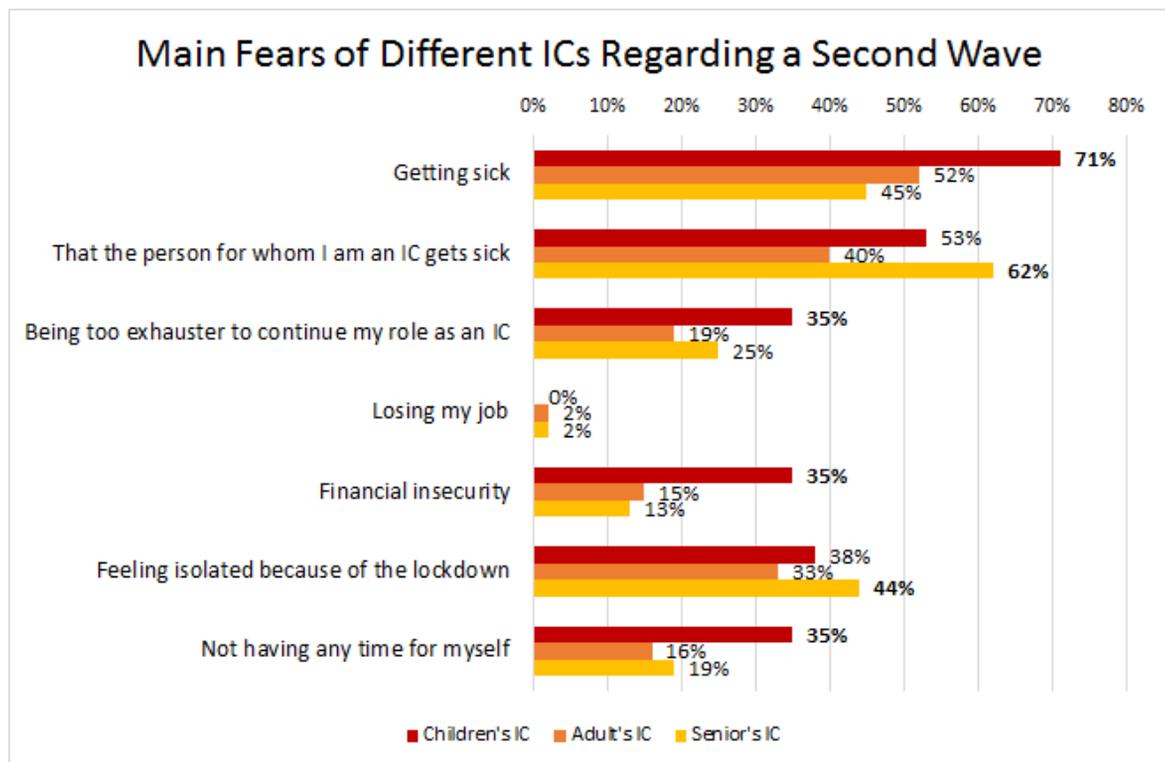
Worries

51% fear that the person they care for will become ill.

49% of informal caregivers fear that they will themselves become ill.

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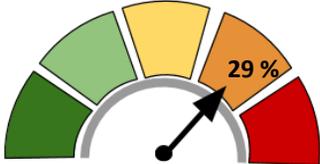
Figure 5 : Main Fears of Different ICs Regarding a Second Wave



APPENDIX A: ILLUSTRATION OF SIGNIFICANT RESPONSES FROM TABLE 1

Since the beginning of the lockdown, informal caregivers have:

Legend : Never Rarely Sometimes Quite often Most of the time	
Felt that they did not have enough money to take care of the person for whom they are an informal caregiver	
Felt like they lost control over their lives	
Felt like they weren't doing enough for the person for whom they are an informal caregiver	
Wished they could leave the care of the person for whom they are an informal caregiver to someone else	
Felt that caring for the person for whom they are an informal caregiver is a burden, a load	
Felt that they wouldn't be able to take care of the person for whom they are an informal caregiver for much longer	

<p>Felt that they lack patience with the person they care for</p>	
<p>Felt isolated from their family and/or friends</p>	
<p>Felt torn between caring for whom they are an informal caregiver and their family and work responsibilities</p>	
<p>Felt that because of the time spent with the person for whom they are an informal caregiver, they didn't have enough time for themselves</p>	

APPENDIX B: QUESTIONS TO THE SURVEY

Q1 - Were you an informal caregiver before the pandemic *

- Yes
- No
- Yes, but I wasn't aware of it

Q2 - If 'Yes', did you receive support services (home help, respite, psychological support, etc.)? (more than one response can apply)

- From a community organization
- From a CLSC
- From an ESSAD
- From a private company
- Other:

Q3 - What services did you receive during containment? (more than one response can apply)

- Home respite
- Out-of-home respite
- Information
- Psychosocial group support via video-conferencing
- Individual psychosocial support via video-conferencing
- Individual psychosocial support by telephone
- Telephone peer support line
- Leisure activities among informal caregivers via video-conferencing
- Bereavement support
- Support for household chores
- Delivery (groceries, meals, medication)
- Transport
- None

Q4 - Quels services auriez-vous aimé obtenir pendant le confinement? (Please select at most 3 answers)

- Home respite
- Out-of-home respite
- Night respite
- Respite home (respite accommodations)
- Information
- Psychosocial group support via video-conferencing
- Individual psychosocial support via video-conferencing
- Individual psychosocial support by telephone
- Telephone peer support line
- Leisure activities among informal caregivers via video-conferencing
- Bereavement support
- Support for household chores
- Delivery (groceries, meals, medication)
- Transport

Q5 – As deconfinement is gradually being put in place, which 3 services would best support you in this post-crisis context? (Please select at most 3 answers)

- Home respite
- Out-of-home respite
- Night respite
- Respite home (respite accommodations)
- Information
- Group psychosocial support
- Individual psychosocial support
- 'Coffee Club'
- Leisure activities among informal caregivers
- Bereavement support
- Support for household chores
- Delivery (groceries, meals, medication)
- Transport

Q6 - Since the beginning of the lockdown, how often have you ... ?

	Never	Rarely	Sometimes	Quite often	Most of the time
Felt like you weren't doing enough for the person for whom you are an informal caregiver?					
Felt that because of the time spent with the person for whom you are an informal caregiver, you didn't have enough time for yourself?					
Felt torn between caring for whom you are an informal caregiver and your other family or work responsibilities?					
Felt that you didn't have enough money to take care of the person for whom you are an informal caregiver?					
Felt that you lack patience with the person you are taking care of?					
Felt that you won't be able to take care of the person for whom you are an informal caregiver for much longer?					
Felt like you've lost control of your life?	<input type="radio"/> <input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
Wished you could leave the care of the person for whom you are an informal caregiver to someone else?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
Felt that caring for the person for whom you are an informal caregiver is a burden, a load?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		

Felt isolated from your family or friends?	○	○	○			
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Q7 - How are you feeling emotionally today?

- I'm usually in a good mood, I look at the bright side of things and I don't worry much.
- I've become more morose, lately I've been more moody.
- I ruminate about a lot of things in my head, I don't laugh a lot. I feel frustrated.
- I'm sometimes happy, sometimes sad, often irritated, I don't know where I'm at, it's starting to get harder and harder to pull myself together.
- I'm pretty sad and irritable and I don't feel like taking care of myself anymore. I feel overwhelmed.
- I'm so sad and irritable that I don't recognize myself so much I've changed. I feel like I'm starting to drown.
- I'm sad to death, I have no patience, I don't feel like doing anything, I just want to cry and sleep all the time.

Q8 -And how do you feel physically?

- I feel fit and I feel like doing a lot of things.
- I have energy, I'm still quite fit, but I have to give up some activities and projects.
- I'm out of shape and have less and less energy. I often feel like sleeping. Every activity requires a lot of effort from me.
- I feel drained and exhausted. I have no energy left to do anything. I feel like nothing can lift me up. I'm completely burned out. I'm discouraged.
- I'm feeling very tired. I wish sleep would be restorative, but it isn't. I always get up so tired in the morning.
- I'm feeling more and more tired. I don't know how I'm going to get back on track. Anyway, everything takes energy even when it's for my own well-being.
- I can't function normally. I just want to do nothing and let myself go. I feel worn out to the core.

Q9 - Were you working before the pandemic?

- Yes
- No

Q10 - If 'Yes', did you work during the pandemic *

- Yes, because essential worker
- Yes, but fewer hours and teleworking
- Yes, same hours in teleworking
- No, because my company has closed/my work doesn't allow teleworking.
- Other:

Q11- Since the deconfinement, did you return to work?

- Yes
- No

Q12 - If 'No', why?

- In accordance with public health, my activity has not yet been allowed to resume.
- I don't have access to a respite or care system for the person I care for (e.g. closed day centres).
- I'm scared of contaminating the person for whom I am an informal caregiver.
- Other: _____

Q13 - During the pandemic, you have access to:

- The CERB

- The CESB
- The CEWS
- Unemployment insurance
- The Compassionate Care Benefit
- Family caregiver benefit for adults
- None

Q14 - During the pandemic, at how much do you estimate your revenue loss when undertaking your role as an informal caregiver?

Q15 - During containment, would you say that your expenses related to your role as an informal caregiver have :

- Decreased
- Increased
- Remained stable

Q16 - At how much do you estimate the additional expenses associated with your role as an informal caregiver during the pandemic?

Q17 - When you think about the possibility of a second wave of the pandemic, what do you fear most? (Please select at most 3 answers)

- Getting sick
- That the person for whom I am an informal caregiver gets sick
- Being too exhausted to continue my role as an informal caregiver.
- Losing my job
- Financial insecurity
- Feeling isolated because of the lockdown.
- Not having time for myself.

Q18 - You are a caregiver : (more than one response can apply)

- For a senior living at (their) home.
- For a senior living in your home.
- For a senior living in accommodation (CHSLD, RI, RPA...).
- For a sick or disabled adult living at (their) home.
- For a sick or disabled adult living in your home.
- For a sick or disabled adult living in accommodation (CHSLR, RI-RTF, RAC...).
- For a sick or disabled child living in your home.
- For a sick or disabled child living in accommodation (RIRTF, RAC...).

Q19 - Did the person for whom you are a caregiver pass away during the pandemic (either because they had COVID-19 or for any other reason)?

- Yes
- No

Q20 - Do you have services to support you in your bereavement?

- An organization for informal caregivers
- An organization specialised in bereavement
- The helpline Deuil
- A psychologist or a health professional from the public sector.
- A psychologist or a health professional from the private sector.
- No support
- Other: _____

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Founded in **2000**, the Regroupement des Aidants Naturels du Québec (RANQ), brings together 102 members, representing more than **22,000 informal caregivers** across Quebec. The RANQ brings together local and regional associations, groups and organizations that have also adopted a mission to improve the living conditions of informal caregivers nationwide. RANQ's mission is to improve the quality of life of informal caregivers in Quebec.

- Raise awareness within the general public and governments of the realities and needs of informal caregivers in Quebec.
- To initiate, participate and broadcast research that promotes a better understanding of the realities of informal caregivers.
- Foster communication and support the sharing of expertise between member organizations.
- Make the needs and rights of informal caregivers known

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