

Supplemental Material

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Supplement 1. Questionnaire

Impact of the COVID-19 Outbreak on and Management Approach for Families with Children on Long-term Kidney Replacement Therapy

Dear caregivers of children on dialysis or after kidney transplantation,

Children with uremia have underlying diseases and impaired immune systems, and that they are more susceptible to novel coronavirus infection. To control the epidemic, various tailored measures are taken nationwide. While these necessary measures may affect the treatment routine and follow-up of children. Here we would like to know the status of novel coronavirus infections among caregivers and children on dialysis or kidney transplantation. Also, we would like to know the medication storage, current difficulties, and future worries you have during this novel coronavirus epidemic. Based on the results of the survey, guidance, help, and possible solution would be offered. Moreover, the results of the survey would hopefully inform the intervention packages and policy recommendations in settings of public health emergency to ensure the quality of life of the families with children on dialysis or transplantation.

The study was approved by the Ethics Board of the Children's Hospital of Fudan University. The ethics number is [2020]-28.

In the survey, you will fill in the information such as the child's name, sex, and telephone number, age, educational background of the primary caregiver, which will be used for contact by the research team when we deliver subsequent interventions. Meanwhile, you will be asked about the situation of novel coronavirus infection in your family members. It will take about 15 minutes to complete the questionnaire. Information such as the child's name, phone numbers will not be public through any form of publication. All electronic questionnaire information will be kept by our research team. Sensitive information such as names will be hidden during the data analysis. The sensitive information such as the child's name will not be known to others except for the research team and will not appear in any media. All information surveyed is only for analysis and used by members of the research team for academic purposes. After the study, the data would be deleted.

If you have any questions regarding this study, please feel free to contact us.

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Are you willing to participate in this study?

Press "willing to participate" to proceed to answer the questionnaire.

Press "No" to leave the page.

Section 1. Basic information of the families with children on long-term kidney replacement therapy

1. Child's name _____

2. Child's sex ☐ male ☐ female

3. Child's ethnicity _____

4. Date of birth of child _____

5. Telephone numbers _____; _____

6. Dialysis/Kidney transplantation follow-up center

- ☐ Children's Hospital of Fudan University
- ☐ Wuhan Children's Hospital of Tongji Medical College, Huazhong University of Science & Technology
- ☐ Affiliated Children's Hospital of Zhengzhou University
- ☐ Children's Hospital of Chongqing Medical University
- ☐ The Second Affiliated Hospital and Yuying Children's Hospital of Wenzhou Medical University
- ☐ Others _____

7. Child's area of residence within one month

_____ (province/cities/districts)

_____ (province/cities/districts)

8. Child's primary caregiver (the one who takes care of the child and familiar with child's medical condition.

For children on PD, the primary caregiver refer to the person who performs dialysis at home)

- ☐ Parents
- ☐ Grandparents
- ☐ Child himself/herself
- ☐ Nannies
- ☐ Others _____

9. Sex of primary caregiver ☐ male ☐ female

10. Age of the primary caregiver _____ years old.

11. Education background of the primary caregiver

- ☐ Illiterate
- ☐ primary school
- ☐ middle school
- ☐ High school or technical secondary school
- ☐ College, bachelor or above

12. The working status during COVID-19 outbreak of the primary caregiver

- ☐ Full-time care
- ☐ Working at home
- ☐ Working at the office (need to travel)

13. Medical payments for the child's current treatment

- ☐ Medical insurance
- ☐ Out-of-pocket

Section 2. COVID-19 Current status in families with children on dialysis or after transplantation

1. Child's COVID-19 current status

- ☐ Under medical observation (isolation after close contact with suspected or confirmed cases)
- ☐ Suspected
- ☐ Confirmed
- ☐ None above

2. COVID-19 current status of members in your family (living together)

- ☐ Someone has been under medical observation (isolation after close contact with suspected or confirmed cases)
- ☐ Someone has been suspected
- ☐ Someone has been confirmed
- ☐ None above

Section 3. Medication supplies storage, current difficulties and future worries of families with children long-term kidney replacement therapy

Section 3.1 Families with children on automatic peritoneal dialysis

1. When did the child's current treatment begin?

_____year_____month

2. So far, to what extent the epidemic of novel coronavirus has influenced the child's treatment?

- ☐ Not at all, just as usual
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Extremely severe

3. To date, how long could the following medication or supplies be used before they run out?

3.1 Peritoneal dialysis fluids

- ☐ Used up or almost used up
- ☐ Within one month
- ☐ From one month to three months
- ☐ More than three month

3.2 Iodine caps

- ☐ Used up or almost used up
- ☐ Within one month
- ☐ From one month to three months
- ☐ More than three month

3.3 Peritoneal dialysis cassettes

- ☐ Used up or almost used up
- ☐ Within one month
- ☐ From one month to three months
- ☐ More than three month

3.4 Hypertensive medication

- ☐ No need to use
- ☐ Used up or almost used up
- ☐ Within one month
- ☐ From one month to three months
- ☐ More than three month

3.5 Erythropoietin (EPO)

- ☐ No need to use
- ☐ Used up or almost used up
- ☐ Within one month
- ☐ From one month to three months
- ☐ More than three month

3.6 Face masks

- ☐ Used up or almost used up
- ☐ Within one month
- ☐ From one month to three months
- ☐ More than three month

3.7 Besides what mentioned above, what other medications or supplies do your kid need in his/her treatment?

_____ How long can it be used before running out? _____

4. What are the difficulties you currently have in your child's treatment? (To choose up to the three most bothering difficulties you currently have)

- ☐ I don't have any difficulties in my child's treatment currently.
- ☐ PD cyclers maintenance ☐ PD supplies shortage ☐ Exit-care supplies shortage ☐ Hand hygiene supplies shortage
- ☐ Face mask shortage ☐ Dialysis related medication shortage ☐ Hard to get EPO injected
- ☐ Hard to access to clinics ☐ Hard to have blood tests ☐ Lack financial support for treatment ☐ Feel fearful or worried
- ☐ Traveling restrictions ☐ delivery service suspended ☐ Others

5. For the next two months, which of the following statements are you most worried about in your child's treatment? (To choose up to the three statements)

- ☐ I don't have any worries about my child's treatment in the next two months.
- ☐ PD supplies shortage ☐ Risk of acquiring COVID-19 ☐ Risk of acquiring COVID-19 during hospital visit
- ☐ Dialysis related medication shortage ☐ Hard to get EPO injected ☐ Hard to access to specialized clinics
- ☐ Hard to have blood tests ☐ Lack financial support for treatment
- ☐ Traveling restrictions ☐ Delivery service suspended ☐ Others

Section 3.2 Families with children on continuous ambulatory peritoneal dialysis

1. When did the child's current treatment begin?

_____year_____month

2. So far, to what extent the epidemic of novel coronavirus has influenced the child's treatment?

- ☐ Not at all, just as usual
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Extremely severe

3. To date, how long could the following medication or supplies be used before they run out?

3.1 Peritoneal dialysis fluids

- ☐ Used up or almost used up
- ☐ Within one month
- ☐ From one month to three month
- ☐ More than three month

3.2 Iodine caps

- ☐ Used up or almost used up
- ☐ Within one month
- ☐ From one month to three month
- ☐ More than three month

3.3 Hypertensive medication

- ☐ No need to use
- ☐ Used up or almost used up
- ☐ Within one month
- ☐ From one month to three month
- ☐ More than three month

3.4 Erythropoietin (EPO)

- ☐ No need to use
- ☐ Used up or almost used up
- ☐ Within one month
- ☐ From one month to three month
- ☐ More than three month

3.5 Face masks

- ☐ Used up or almost used up
- ☐ Within one month
- ☐ From one month to three month
- ☐ More than three month

3.6 Besides what mentioned above, what other medications or supplies do your kid need in his/her treatment?

_____ How long can it be used before running out? _____

4. What are the difficulties you currently have in your child's treatment? (To choose up to the three most bothering difficulties you currently have)

- ☐ I don't have any difficulties in my child's treatment currently.
- ☐ PD supplies shortage ☐ Exit-care supplies shortage ☐ Hand hygiene supplies shortage
- ☐ Face mask shortage ☐ Dialysis related medication shortage ☐ Hard to get EPO injected
- ☐ Hard to access to clinics ☐ Hard to have blood tests ☐ Lack financial support for treatment ☐ Feel fearful or worried
- ☐ Traveling restrictions ☐ delivery service suspended ☐ Others

5. For the next two months, which of the following statements are you most worried about in your child's treatment? (To choose up to the three statements)

- ☐ I don't have any worries about my child's treatment in the next two months.
- ☐ PD supplies shortage ☐ Risk of acquiring COVID-19 ☐ Risk of acquiring COVID-19 during hospital visit
- ☐ Dialysis related medication shortage ☐ Hard to get EPO injected ☐ Hard to access to specialized clinics
- ☐ Hard to have blood tests ☐ Lack of financial support for treatment
- ☐ Traveling restrictions ☐ Delivery service suspended ☐ Others

Section 3.3 Families with children on hemodialysis

1. When did the child's current treatment begin?

_____year_____month

2. So far, to what extent the epidemic of novel coronavirus has influenced the child's treatment?

- ☐ Not at all, just as usual
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Extremely severe

3. To date, how long could the following medication or supplies be used before they run out?

3.1 Hypertensive medication

- ☐ No need to use
- ☐ Used up or almost used up
- ☐ Within one month

- From one month to three month
- More than three month

3.2 Face masks

- Used up or almost used up
- Within one month
- From one month to three month
- More than three month

3.3 Besides what mentioned above, what other medications or supplies do your kid need in his/her treatment?

_____, how long can it be used before running out? _____

4. What are the difficulties you currently have in your child's treatment? (To choose up to the three most bothering difficulties you currently have)

- I don't have any difficulties in my child's treatment currently.
- Hand hygiene supplies shortage ○ Face mask shortage ○ Dialysis related medication shortage
- Hard to get EPO injected ○ Hard to access to clinics ○ Hard to have blood tests
- Lack of financial support for treatment ○ Feel fearful or worried
- Traveling restrictions ○ Delivery service suspended ○ Others

5. For the next two months, which of the following statements are you most worried about in your child's treatment? (To choose up to the three statements)

- ○ I don't have any worries about my child's treatment in the next two months.
- Risk of acquiring COVID-19 ○ Risk of acquiring COVID-19 during hospital visit
- Dialysis related medication shortage ○ Hard to get EPO injected ○ Hard to access to specialized clinics
- Hard to have blood tests ○ Lack financial support for treatment
- Traveling restrictions ○ Delivery service suspended ○ Others

Section 3.4 Families with children after kidney transplantation

1. When did the child's current treatment begin?

_____year _____month

2. So far, to what extent the epidemic of novel coronavirus has influenced the child's treatment?

- Not at all, just as usual
- Mild
- Moderate
- Severe
- Extremely severe

3. To date, how long could the following medication or supplies be used before they run out?

3.1 Immunosuppressants

- Used up or almost used up
- Within one month
- From one month to three month
- More than three month

3.2 Hypertensive medication

- No need to use
- Used up or almost used up
- Within one month
- From one month to three month
- More than three month

3.3 Face masks

- Used up or almost used up
- Within one month
- From one month to three month
- More than three month

3.4 Besides what mentioned above, what other medications or supplies do your kid need in his/her treatment?

_____ How long can it be used before running out? _____

4. What are the difficulties you currently have in your child's treatment? (To choose up to the three most bothering difficulties you currently have)

- I don't have any difficulties in my child's treatment currently.
- Hand hygiene supplies shortage ○ Face mask shortage ○ kidney transplantation related medication shortage
- Hard to get EPO injected ○ Hard to access to clinics ○ Hard to have blood tests
- Lack financial support for treatment ○ Feel fearful or worried
- Traveling restrictions ○ Delivery service suspended ○ Others

5. For the next two months, which of the following statements are you most worried about in your child's treatment? (To choose up to the three statements)

- I don't have any worries about my child's treatment in the next two months.
- Risk of acquiring COVID-19 ○ Risk of acquiring COVID-19 during hospital visit
- KT related medication shortage ○ Hard to get EPO injected ○ Hard to access to specialized clinics
- Hard to have blood tests ○ Lack financial support for treatment
- Traveling restrictions ○ Delivery service suspended ○ Others

Section 4. Psychological status of the caregivers with children on long-term kidney replacement therapy

1. Over the last 2 weeks, as your kid's primary caregiver, how often have you been bothered by any of the following problems?

1.1 Little interest or pleasure in doing things

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

1.2 Feeling down, depressed, or hopeless

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

1.3 Trouble falling or staying asleep, or sleeping too much

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

1.4 Feeling tired or having little energy

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

1.5 Poor appetite or overeating

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

1.6 Feeling bad about yourself or that you are a failure or have let yourself or your family down

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

1.7 Troubling concentrating on things, such as reading the newspaper or watching television

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

1.8 Moving or speaking so slowly that other people could have noticed, or the opposite being so fidget or restless that you have been moving around a lot more than usual

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

1.9 Thoughts that you would be better off dead or of hurting yourself

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

2. Over the last 2 weeks, as your kid's primary caregiver, how often have you been bothered by any of the following problems?

2.1 Feeling nervous, anxious or on edge

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

2.2 Not being able to stop or control worrying

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

2.3 Worrying too much about different things

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

2.4 Trouble relaxing

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

2.5 Being so restless that it is hard to sit still

- ☐ not at all ☐ several days ☐ more than half the days ☐ nearly every day

2.6 Becoming easily annoyed or irritable

- not at all
- several days
- more than half the days
- nearly every day

2.7 Feeling afraid as if something awful might happen

- not at all
- several days
- more than half the days
- nearly every day

Supplemental Table 1.

Unadjusted analyses of the prevalence of caregivers' depressive symptoms and anxiety

	Depressive symptoms N=29	Unadjusted Odds Ratio (95% CI)	P Values	Anxiety N=24	Unadjusted Odds Ratio (95% CI)	P Values
Children's age (years old)	-	0.88 (0.80 to 0.96)	0.004 ^a	-	0.88 (0.80, 0.97)	0.007 ^a
Children's sex (%)						
<i>Male</i>	15 (13)	Reference		13 (11)	Reference	
<i>Female</i>	14 (14)	1.14 (0.52 to 2.49)	0.74 ^c	11 (11)	1.01 (0.43 to 2.38)	0.97 ^c
Children's ethnicity (%)						
<i>Han</i>	29 (14)	Reference		23 (11)	Reference	
<i>Minority groups</i>	0 (0)	-	0.43 ^c	1 (10)	0.90 (1.1 to 7.46)	0.93 ^c
Current treatment modalities (%)						
<i>Dialysis</i>	20 (18)	Reference		17 (15)	Reference	
<i>Kidney transplantation</i>	9 (8)	0.43 (0.19 to 0.99)	0.04 ^a	7 (7)	0.40 (0.16 to 0.99)	0.04 ^a
Duration on treatment (months)	-	0.99 (0.97 to 1.01)	0.26 ^c	-	0.99 (0.96 to 1.01)	0.19 ^b
Caregivers (%)						
<i>Parents</i>	28 (15)	Reference		24 (13)	Reference	
<i>Grandparents</i>	0 (0)	-		0 (0)	-	
<i>Children by themselves</i>	1 (8)	0.49 (0.06 to 3.90)	0.50 ^c	0 (0)	-	
<i>Others</i>	0 (0)	-		0 (0)	-	
Caregivers' sex (%)						
<i>Male</i>	6 (16)	Reference		4 (11)	Reference	
<i>Female</i>	23 (13)	0.74 (0.27 to 1.97)	0.74 ^c	20 (11)	1.01 (0.33 to 3.16)	0.98 ^c
Caregivers' age (years old)	-	0.97 (0.93 to 1.01)	0.14 ^b	-	0.98 (0.94 to 1.02)	0.37 ^c
Caregivers' educational background (%)						
<i>Illiterate, primary school or middle school</i>	16 (13)	Reference		15 (13)	Reference	
<i>High school or equivalent</i>	11 (14)	1.01 (0.44 to 2.31)	0.98 ^c	7 (9)	0.66 (0.26 to 1.69)	0.38 ^c
<i>Bachelor's degree and above</i>	2 (10)	0.72 (0.15 to 3.38)	0.67 ^c	2 (10)	0.77 (0.16 to 3.66)	0.74 ^c
Caregivers' working status during the outbreak (%)						
<i>Full-time care</i>	28 (14)	Reference		23 (12)	Reference	
<i>Working at home</i>	1 (5)	0.30 (0.04 to 2.30)	0.25 ^c	1 (5)	0.38 (0.05 to 2.9)	0.35 ^c
<i>Working at office (need to travel)</i>	0 (0)	-		0 (0)	-	
Medical payment (%)						
<i>Insurance</i>	23 (12)	Reference		18 (9)	Reference	
<i>Out-of-pocket</i>	6 (21)	1.91 (0.70 to 5.17)	0.32 ^c	6 (21)	2.51 (0.90 to 6.96)	0.14 ^b

^a <0.05; ^b 0.05 - 0.20; ^c >0.20;

- not applicable

Supplemental Table 2. Associations of treatment modality with the prevalence of depressive symptoms and anxiety in caregivers with children on long-term kidney replacement therapy

		Adjusted odds ratio (95% CI)	
	N (%)	Model 1	Model 2
Depressive symptoms			
Dialysis*	20 (18)	1 (ref)	1 (ref)
Transplantation	9 (8)	0.53 (0.22 to 1.29)	0.46 (0.17 to 1.23)
Anxiety			
Dialysis*	17 (15)	1 (ref)	1 (ref)
Transplantation	7 (7)	0.97 (0.33 to 2.85)	1.10 (0.31 to 2.85)

* Dialysis as reference

Model 1. Adjusted for children's age, duration on treatment, caregivers' age, caregivers' sex, medical payment for kidney replacement therapy.

Model 2. Adjusted for children's age, duration on treatment, caregivers' age, caregivers' sex, medical payment for kidney replacement therapy in the Shanghai center.