

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

Appendix A. People Receiving Hemodialysis and caregivers survey



Chronic Disease
Innovation Centre

Rady Faculty of
Health Sciences



University
of Manitoba



SEVEN OAKS GENERAL HOSPITAL

Introduction:

Thank you for your interest in this survey. This survey is part of a study under the Can-SOLVE CKD network. Can-SOLVE CKD is a research group in Canada that wants to make kidney care better by including people receiving medical care in research. We work with people with long-term kidney problems, those receiving dialysis, and those who have had or are receiving kidney transplant. The goal of this study is to improve mental health care for people receiving hemodialysis.

Why Mental Health Care Matters:

“Mental health” refers to the state of a person’s psychological and emotional well-being. It’s how they feel and think inside. It’s about their feelings and thoughts, whether they are experiencing positive emotions, such as happiness and contentment, or facing challenges like stress, sadness, or anxiety.

Many people who are receiving hemodialysis have mental health concerns, but they don't always get the help they need. We are doing a survey across Canada to know what matters most to people who are receiving hemodialysis when it comes to mental health care. This survey is the first step to finding ways to improve their mental health care.

What the Survey Covers:

In the survey, we will ask you about mental health concerns specific to people receiving hemodialysis. We also want to know how these concerns can be addressed and what you think is missing in mental health care for people who receive hemodialysis.

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

People who are receiving hemodialysis and their caregivers can answer this survey. If you take care of someone receiving hemodialysis, please answer the questions about the person you care for.

How to Answer:

To answer the questions, put a checkmark in the box that fits you best. Some questions also give you space to write more about your answers. If you prefer, you can also do the survey online at www.betterkidneycare.ca.

Keeping It Private:

Your answers in this survey will be anonymous, which means we won't know who filled it out once you give it back to us. Completing and returning the survey means that you want to participate in this study and will act as your consent. If you choose to do the survey on paper, place it in the envelope we provided and give it to your hemodialysis nurse. The University of Manitoba Research Ethics Board and St. Boniface Hospital may review research-related records for quality assurance purposes.

Mental Health Support:

If you need mental health support as a result of participating in this study, you may:

i.) ask for a renal social worker in your hemodialysis unit.

Or

ii.) Visit the link on your phone/tablet/computer and select the catalogue of available mental health resources that is specific to your province: <https://healthygol.com/kidney>

This study has been approved by the University of Manitoba Health Research Ethics Board. For any questions you may have, please contact:

Russell Malabanan

Research Coordinator

Ph: (204) 631-3834

E-mail: rmalabanan@sogh.mb.ca

Dr. Clara Bohm

Principal Investigator/Researcher

Ph: (204) 631-3834

E-mail: cbohm@sogh.mb.ca

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

A. People Receiving Hemodialysis and Caregiver SURVEY

Note: If you take care of someone receiving hemodialysis, please answer the questions about the person you care for.

“**Mental health**” refers to the state of a person’s psychological and emotional well-being. It’s how they feel and think inside. It’s about their feelings and thoughts, whether they are experiencing positive emotions, such as happiness and contentment, or facing challenges like stress, sadness, or anxiety.

1) Has kidney disease affected your mental health?

☐ Yes

☐ No

If “**Yes**”, Please explain how so:

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

2) Has receiving hemodialysis care affected your mental health?

☐ Yes

☐ No

If **“Yes”**, Please explain how so:

“Mental health support or resources” are different ways that people can get help when they are having problems with their mental health. There are different kinds of support available, depending on where you go for help. Some examples include getting help from professionals like counsellors or therapists, getting support from friends and family who understand your feelings, getting help during a crisis, and getting assistance from community organizations or groups that want to help.

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

3) Have you sought mental health support since you started receiving hemodialysis?

☐

Yes

☐

No

If **“Yes”**, please explain what type of support you sought and why you chose it:

4) Have you been referred to any mental health resources since you started receiving hemodialysis?

☐

Yes

☐

No

If **“Yes”**, please explain:

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

A **mental health specialist or provider** is a person who works in healthcare and helps with problems related to mental health. Some examples of mental health specialists are psychologists, social workers, family therapists, psychiatrists, Knowledge Keepers, and spiritual practitioners. They have special training and knowledge to provide support and care for people with mental health problems.

Referred means that a doctor or healthcare professional is sending you to another doctor or specialist for additional help or advice.

5) Have you been **referred** to a mental health specialist since you started receiving hemodialysis?

☐ Yes

☐ No

If **“Yes”**:

i. Who referred you:

ii) To whom were you referred to?

If **“No”**:

i. Would you have liked to have been referred to a mental health specialist?

☐ Yes

☐ No

6) Have you **seen** a mental health specialist since starting hemodialysis? (**Seen** means having gone to a specialist).

☐ Yes

☐ No

If **“Yes”**:

i. Were you satisfied with how the visit went?

☐ Yes

☐ No

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

ii. Please explain why you were or were not satisfied:

7) What do you think are the biggest mental health challenges for someone receiving hemodialysis? (List 3 challenges)

Challenge1.)_____

Challenge2.)_____

Challenge3.)_____

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

8) If there was a mental health care provider available in the hemodialysis unit, would you be interested in seeing them?

☐ Yes

☐ No

Please explain:

9) Do you think that the mental health care provider needs to be familiar with the specific circumstances for people receiving hemodialysis?

☐ Yes

☐ No

Please explain:

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

10) If there was a mental health care provider available, would you prefer to be seen (check all that apply to you):

- ☐ In-person at your dialysis station
- ☐ In-person in a private clinic room outside of dialysis
- ☐ Virtually or online
- ☐ By telephone
- ☐ Other: _____

Please explain why you prefer this/these method(s):

11) What mental health resources do you think would be most useful for people receiving hemodialysis? (For example, things like peer support, online or print materials, one-on-one counselling, and others)

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

Note: On this page, we would like to know more about **you** (the person completing the survey):

Please mark the box beside the best answer for each question:

12) Please indicate if you are a/an:

- ☐ Individual receiving hemodialysis
- ☐ Caregiver of an individual receiving hemodialysis
- ☐ Prefer not to answer

13) How long have you / the person you are providing care for, been on dialysis?

- ☐ Less than 3 months
- ☐ 3-6 months
- ☐ 6 months – 1 year
- ☐ 1 year - 3 years
- ☐ 3 years - 5 years
- ☐ More than 5 years
- ☐ Don't know
- ☐ Not applicable

14) What is your age?

- | | |
|--------------------------------|---|
| ☐ 18-34 | ☐ 65-79 |
| ☐ 35-49 | ☐ 50-64 |
| ☐ 50-64 | ☐ Prefer not to answer |

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

15) What is your gender?

- ☐ Woman
- ☐ Man
- ☐ I self-identify as _____
- ☐ Don't know
- ☐ Prefer not to answer

16) What is your ethnic group?

- ☐ White
- ☐ Indigenous (First Nations, Inuit, Métis)
- ☐ East Asian
- ☐ South Asian
- ☐ African-Canadian/Caribbean Canadian
- ☐ Other: I self identify as _____
- ☐ Don't know
- ☐ Prefer not to answer

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

17) Which part of Canada do you live in?

- ☐ Atlantic
- ☐ Quebec
- ☐ Ontario
- ☐ Alberta
- ☐ Saskatchewan
- ☐ Manitoba
- ☐ Northwest Territories
- ☐ Nunavut
- ☐ British Columbia
- ☐ Yukon
- ☐ Prefer not to answer

18) Did you have to move to a different place (city or town) to receive facility-based hemodialysis?

- ☐ Yes
- ☐ No
- ☐ Prefer not to answer

END

Thanks for being a part of this survey! Your help is important in improving mental health care for people who receive hemodialysis in Canada. We appreciate your time and effort in completing the survey, as your answers will make a big difference in how we care for people with kidney problems.

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

Appendix B. Healthcare Provider Survey



Chronic Disease
Innovation Centre

Rady Faculty of
Health Sciences



University
of Manitoba



SEVEN OAKS GENERAL HOSPITAL

Thank you for taking the time to participate in this survey. This survey is part of a study under the Can-SOLVE CKD Network. Can-SOLVE CKD is a large Canadian research network aimed at improving kidney care by taking a people-centred approach to research. This approach involves people who are living with chronic kidney disease (CKD), receiving dialysis care, and receiving/ have received kidney transplant in the research process. The goal of this research study is to identify and address priorities for improving mental health care for individuals receiving hemodialysis.

Mental health concerns for people receiving hemodialysis (HD) are disproportionately high and undertreated. In this phase of the study, we are conducting a pan-Canadian survey to provide a summary of participants' priorities for improving mental health care gaps for people receiving HD, as well as their reasons for these suggestions. Our next step will be to design and test solutions to these priorities and challenges by gaining input from healthcare providers who have experience working in HD like you!

This survey will help us to determine the top priorities for mental health resources and mental health care for people receiving in-centre HD across Canada. We will ask you questions about mental health concerns that are specific to people receiving HD, how those concerns can be addressed and what your top priorities are to fill the current mental health care gaps in HD care in Canada. You can complete this survey online at: www.betterkidneycare.ca

This short survey is anonymous and we will not be able to identify who completes the survey. Completing the survey indicates your willingness to participate in the study and will serve as your consent. The University of Manitoba Research Ethics Board and St. Boniface Hospital may review research-related records for quality assurance purposes.

This study has been approved by the University of Manitoba Health Research Ethics Board. For any questions you may have, please contact:

Russell Malabanan

Research Coordinator

Ph: (204) 631-3834

E-mail: rmalabanan@sogh.mb.ca

Dr. Clara Bohm

Principal Investigator/Researcher

Ph: (204) 631-3834

E-mail: cbohm@sogh.mb.ca

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

“Mental health” refers to the state of one’s psychological and motional well-being. It refers to how they feel and think inside. It's about their feelings and thoughts, whether they are experiencing positive emotions, such as happiness and contentment, or facing challenges like stress, sadness, or anxiety. This is not the same as mental illness, but poor mental health can lead to physical and mental illness.

1) Has kidney disease affected the mental health of the people receiving hemodialysis that you care for?

☐ Yes

☐ No

If **“Yes”**, please explain how so:

2) Among the people that you care for, have you observed any mental health issues as a result of receiving hemodialysis?

☐ Yes

☐ No

If **“Yes”**, please explain what you have observed:

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

3) What mental health concerns have you observed in/heard from the people receiving hemodialysis that you care for?

Please explain:

Mental health support/resources refer to various forms of assistance, care, and resources provided to individuals who are experiencing mental health challenges. These services and care may include both professional and non-professional support, depending on where the services are provided. Such support may include emotional support from friends and family, counselling and therapy from licensed professionals, crisis intervention, support from community organizations and non-profits, etc.

4) Have you referred a person receiving in-centre hemodialysis to any mental health resources?

☐ Yes

☐ No

Please explain:

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

5) What mental health stressors or pressures specific to hemodialysis have you witnessed among the people receiving in-centre hemodialysis that you care for?

Mental health specialist/provider refers to any healthcare work who helps with the care of mental health problems (example: psychologist, social worker, family therapist, psychiatrist, Knowledge Keeper, spiritual practitioner, etc.)

6) Have you referred an individual receiving in-centre hemodialysis to see a mental health specialist?

☐ Yes

☐ No

Please explain:

7) In your opinion, what are the biggest mental health challenges you have observed in people receiving hemodialysis? (List up to 3 challenges)

Challenge1.) _____

Challenge2.) _____

Challenge3.) _____

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

8) Do you think having a dedicated mental health care provider available in the hemodialysis unit would be beneficial for people receiving hemodialysis?

☐ Yes

☐ No

Please explain:

9) Do you think that mental health care providers for people receiving hemodialysis need to be familiar with the specific circumstances related to hemodialysis?

☐ Yes

☐ No

Please explain:

10) How do you think we can best fill the current mental health care gaps in hemodialysis care in Canada? Please provide any other related comments:

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

On this page, we will end with some questions about you. Please mark the box beside the best answer for each question:

11) What is your role in the hemodialysis unit?

- ☐ Nephrologist
- ☐ Nurse (RN and LPN)
- ☐ Nurse Practitioner
- ☐ Pharmacist
- ☐ Social Worker
- ☐ Dietitian
- ☐ Other (please specify): _____
- ☐ Prefer not to answer

12) What is your age?

- ☐ 18-34
- ☐ 35-49
- ☐ 50-64
- ☐ 65-79
- ☐ 80 +
- ☐ Prefer not to answer

13) What is your gender?

- ☐ Woman
- ☐ Man
- ☐ I self identify as _____
- ☐ Don't know
- ☐ Prefer not to answer

Mind the Gap: Addressing Mental Health Care Gaps for Canadians Receiving Facility-Based Hemodialysis

14) What is your ethnic group?

- ☐ White
- ☐ Indigenous (First Nations, Inuit, Métis)
- ☐ East Asian
- ☐ South Asian
- ☐ African-Canadian/Caribbean Canadian
- ☐ Other: I self-identify as _____
- ☐ Don't know
- ☐ Prefer not to answer

15) Which part of Canada do you live in?

- ☐ Atlantic
- ☐ Quebec
- ☐ Ontario
- ☐ Alberta,
- ☐ Saskatchewan
- ☐ Manitoba
- ☐ Northwest Territories
- ☐ Nunavut
- ☐ British Columbia
- ☐ Yukon
- ☐ Prefer not to answer

END

Thanks for being a part of this survey! Your help is important in improving mental health care for people who receive hemodialysis in Canada. We appreciate your time and effort in completing the survey, as your answers will make a big difference in how we care for people with kidney problems.