

Supplemental Material

Supplemental Table 1. COREQ 32-item checklist for interviews.¹⁶

Item	Description/ Related Questions
Domain 1: Research team and reflexivity	
1. Interviewer	Adeline Dorough
2. Credentials	Master of Public Health
3. Occupation	Research Coordinator
4. Gender	Female
5. Experience and training	Ms. Dorough is a master's-level trained public health professional experienced in qualitative interviewing, analysis, and reporting. She has 3 years of research experience working directly with individuals receiving maintenance hemodialysis and dialysis care providers.
6. Relationship established	None
7. Participant knowledge of the interviewer	None The interviewer introduced herself at the beginning of the interviews as non-clinician and member of the research team.
8. Interviewer characteristics	Prior to providing written informed consent, participants were briefed on the interview purpose, informed of research participation rights, and made aware that responses would remain confidential. No interviewer-related biases identified.
Domain 2: Study Design	
9. Methodological orientation and theory (page 6)	Thematic analysis ^{24,25}
10. Sampling (page 4)	<u>Patients:</u> Purposive from individuals receiving in-center hemodialysis at 2 NC dialysis clinics. Factors considered included: age, sex, race, education level, and dialysis vintage. <u>Care partners:</u> Snowball from patient participants. <u>Care providers:</u> Purposive from individuals working in 4 NC dialysis clinics. The primary factor considered was professional role (nurse, dietician, social worker, medical provider) and clinic size.
11. Method of approach (pages 4)	Participants were recruited until data saturation was reached (no new codes identified after 3 consecutive interviews).
12. Sample size (page 6)	13 patients, 3 care partners, 4 medical providers, and 5 clinic personnel
13. Non-participation	Of the 18 hemodialysis patients invited to participate, 13 (72%) participated. Of the 5 care partners invited to participate, 3 (75%) participated. Of the 13 clinic personnel invited to participate, 9 (69%) participated. Reasons for non-participation included: patients – could not be reached (n=2), scheduling conflict (n=1), transient status (n=1), and Spanish-speaking (n=1); care partners – could not be reached (n=1) and interview scheduling conflict (n=1); medical provider and clinic personnel – left position (n=1) and scheduling conflict (n=3).
14. Setting of data collection (pages 4)	In-person interviews were conducted in private settings based on availability and participant preference: dialysis clinic conference rooms, administrative offices, or alternative participant-selected locations.
15. Presence of non-participants	None
16. Description of sample (page 19)	See Table 1
17. Interview guide (Supplement pages 3-5)	The semi-structured interview guide was developed based on literature review and research team/stakeholder panel input. It included open-ended questions about life goals, care planning knowledge and experiences. See Supplemental Table 2.
18. Repeat interviews	N/A
19. Audio/visual recording (pages 4, 5)	Digitally recorded
20. Field notes (page 6)	The interviewer took notes on participant non-verbal body language, interview setting and reasons for interview guide question adaptations to provide additional context for participant responses.
21. Duration (page 19)	34-85 minutes (see Table 1)

22. Data saturation (page 6)	Interviews were ceased when no new codes were identified after 3 consecutive interviews (data saturation).
23. Transcriptions returned	Complete interview transcripts were not shared with participants.
Domain 3: Analysis and Findings	
24. Number of data coders (page 6)	2
25. Description of coding tree (pages 5-6)	Interviews were analyzed using thematic analysis rooted in the principles of Clarke and Braun. ^{24,25} Two study team members (AD, SLM) inductively identified concepts within transcripts, and coded the relevant interview text by concept.
26. Derivation of themes (pages 5-6)	Three team members (AD, JEF, SLM) iteratively discussed related concepts and subsequently synthesized themes/subthemes (research triangulation). Data were pooled across participant types after team members identified overlap across concepts in patient, care partner, and care provider transcripts. Returning to the source data (transcripts) to verify findings, the three developed a thematic schema that accurately reflected the data.
27. Software (page 5)	ATLAS.ti (Berlin, Germany)
28. Participant checking	No formal participant checking upon interview transcription
29. Quotations presented (pages 20-21 and Supplement page 7)	See Table 2 and Supplemental Table 3.
30. Data and findings consistent	Consistent
31. Clarity of major themes (pages 7-9)	Five major themes were identified: feeling boxed in by the system, navigating dual lives, acknowledging an evolving identity, respecting the individual as a whole person, and increasing individualization to enhance care. Figure 1 depicts interrelationships among themes.
32. Clarity of minor themes (pages 7-9)	Two of the five major themes contained subthemes: feeling boxed in by the system – checking task-oriented boxes, surrendering to the weight of the system, being influenced by historical experiences; navigating dual lives – experiencing isolation, making trade-offs.

Supplemental Table 2. Concept elicitation and cognitive interview guide topics, questions and probes.

Concept Elicitation Patient and Care Partner Interview Guide	
1. Welcome	
2. Ground Rules	
3. Introduction	
4. Perspectives on life goals	<p>Q. What does the phrase “life goal” mean to you?</p> <p>Q. What is important to you? PROBE: What do you care most about in life and why? PROBE: What is the most enjoyable part of your life? PROBE: What do you want to be able to do that you cannot? PROBE: What is your greatest dream? PROBE: What do you wish to accomplish in your life?</p>
5. Perspectives on moderators of life goals	<p>Q. You have mentioned several life goals (list examples). How, if at all, does dialysis get in the way of you achieving these goals? PROBE: What would you like to be doing that is made difficult by dialysis? PROBE: How has dialysis affected your ability to do things you enjoy? PROBE: How does the way you feel during or after dialysis affect your ability to do things you enjoy?</p> <p>Q. We have been talking about how dialysis sometimes gets in the way of things that are important to you. What other things get in the way? PROBE: Any medical conditions that require a lot of management? (e.g. for some, blood sugar checks and insulin administration) PROBE: Any challenges at home? Like money worries? Difficulty with transportation? Responsibilities caring for other people in your family or home?</p>
6. Perspectives on life goals and dialysis care plans	<p>Q. Have you talked about your life goals (list some of stated goals as a reminder) with members of your dialysis team? PROBE: If so, who? Who brought it up? Was the discussion helpful? If so, how? If not, why not? PROBE: Do you feel like your life goals are considered in decisions about your dialysis care? What about in decisions about other aspects of your medical care? Why or why not? PROBE: Do you remember your life goals ever being discussed as part of your annual dialysis care plan?</p> <p>Q. How might your dialysis care team help you reach your life goals? PROBE: Can you imagine any changes to your dialysis treatment or medical care that might help you achieve your life goals? If yes, what are some examples? PROBE: Is there a particular person (e.g. social worker, nephrologist, nurse) with whom you would prefer to discuss your goals? PROBE: How often would you like to discuss your goals? PROBE: How would you feel about incorporating a discussion of your life goals and the things that prevent you from achieving them into the dialysis care plan?</p> <p>Q. How might discussing goals with your dialysis care team influence your dialysis treatment? PROBE: How would you like to see your goals influence your treatment? PROBE: If your dialysis care team could help identify dialysis treatment changes or other changes to your treatment plan that might help you achieve your life goals, would you be willing to try them? Why or why not?</p> <p>Q. What are your thoughts about the existing approach to dialysis care plans? PROBE: Does the existing care planning process feel “meaningful”? PROBE: What are your ideas about ways to improve the existing care plan approach?</p> <p>Q. If a discussion of your life goals were to be included in dialysis care planning, what kinds of questions would you like your dialysis care team to ask you? PROBE: What kinds of tools (e.g. examples of goals, templates) might be helpful in preparing you for these conversations?</p>

	<p>PROBE: Where and when should the conversations be held? (<i>i.e.</i> dialysis vs. non-dialysis day; on treatment floor vs. conference room)</p> <p>PROBE: Who should be present for these conversations?</p> <p>PROBE: How often would you like to have follow-up about these conversations?</p>
7. Perspectives on meaningful measurement	<p>Q. In your opinion, what is quality dialysis care? PROBE: Any ideas about how you might measure it?</p> <p>Q. If you were going to measure how well a patient's dialysis care aligned (or matched) with his/her goals, how would you do it? PROBE: Ask the patient? If, yes, what kinds of questions would be important to ask? PROBE: Ask a member of the dialysis care team? If so, who? PROBE: Evaluate the medical record to see if life goal discussions were documented? PROBE: Other ideas?</p>

Concept Elicitation Care Provider (Clinic Personnel and Medical Provider) Interview Guide

1. Welcome	
2. Ground Rules	
3. Introduction	
4. Perspectives on existing dialysis care planning process	<p>Q. What are your thoughts about the existing approach to dialysis care plans? PROBE: Do you feel like the current structure helps you know and treat your patients? If yes, how? If no, why not? PROBE: Does the existing care planning process feel "meaningful"? Why or why not? PROBE: How are your patients involved in the care planning process? PROBE: Who else is included in the care plan discussion? Do you include family or friends? If no, why not? PROBE: Do you feel like you tailor dialysis treatment plans to the individual? If yes, how? If no, why not? PROBE: Do your patients have access to (a copy of) their care plan? If not, why not? PROBE: What are your ideas about ways to improve the existing care plan approach?</p> <p>Q. Do you feel like the current care plan structure helps you learn what is important to patients? If yes, how? If no, why not?</p>
5. Perspectives on eliciting goals from patients	<p>Q. Do you talk to patients about their goals? If yes, in what way? If no, why not? PROBE: What kinds of goals do your patients have? PROBE: Did the conversations cause you to change the patient's dialysis treatment plan? If yes, what kind of changes were made? PROBE: Did you share what you learned with other members of the care team? PROBE: Did you document the conversation? If yes, where?</p> <p>Q. What do you think would happen if you routinely started asking patients about their goals? PROBE: Would it improve your ability to care for them? If yes, how? If no, why not? PROBE: Can you think of any unintended consequences that might occur? Please give some examples. How might these be avoided?</p> <p>Q. How equipped do you feel to engage in discussion about goals with your patients? PROBE: What could be done to make you more comfortable?</p>
6. Perspectives on goal moderators	<p>Q. How, if at all, do you think that dialysis gets in the way of patients achieving their goals?</p> <p>Q. Let's take a hypothetical example and imagine how knowing a patient's goals and understanding what barriers prevent her from achieving those goals might help you make dialysis treatment decisions. Let's say a patient told you that she derived great joy from playing with her grandchildren, but that she was not able to play with them after dialysis treatments because she is so tired. How do you think you knowing this information could impact her care? PROBE: Would knowing this information prompt you to make any changes in her care? PROBE: If yes, what would you change? If no, why not?</p> <p>Q. We have been talking about how dialysis sometimes gets in the way of things that are important to patients. What other things do you think get in the way?</p>

	<p>PROBE: Do you think knowing about these barriers to goal achievement would help you better care for your patients? If yes, how?</p>
7. Perspectives on implementation of goal-directed care planning	<p>Q. How might you as a dialysis care team member help patients reach their goals? PROBE: Can you imagine changes to the dialysis treatment or medical care that might help patients achieve their goals? If yes, what are some examples? PROBE: Is there a particular person (e.g. social worker, nephrologist, nurse) with whom you think it would be best for patients to discuss their goals?</p> <p>Q. If a discussion of patient goals was to be included in dialysis care planning, what kinds of tools (e.g. examples of goals, templates) might be helpful in preparing for these conversations?</p>

Cognitive Interview Patient and Care Partner Interview Guide

1. Welcome	
2. Ground Rules	
3. Introduction	
4. Overall impression and general thoughts	<p>Q. What was your overall impression of the materials?</p> <p>Q. What was it like to read the materials? PROBE: How easy or hard was it to understand? PROBE: How did you feel about the length? PROBE: How is the font size?</p> <p>Q. What did you think of the different sections? PROBE: How does the information flow? PROBE: What, if anything would you change about the layout? Formatting?</p>
5. Section by section materials review	<p>Q. What did you think about [XX] section? PROBE: Which is the most helpful part of this section? PROBE: Was anything confusing? Unclear? Misleading? Missing? PROBE: What other information would be helpful to include?</p> <p>Q. What did you think of the example patient priorities included?</p> <p>Q. What does “person-centered dialysis care planning” mean to you?</p> <p>Q. What did you think about the three steps in the care planning process? PROBE: Is anything missing? If yes, what? PROBE: How could we describe the process more clearly?</p> <p>Q. What did you think about the instructions for preparing for the meeting? PROBE: What do you think about the preparation questions? PROBE: Which questions are the most important for your care team to ask? PROBE: What other questions might be helpful in preparing for the meeting?</p> <p>Q. What do you think of the description about follow-up? PROBE: What does “...how your plan is working for you” mean to you?</p> <p>Q. What does the term “individualized” mean to you?</p> <p>Q. How might extra information about this process be helpful to you? PROBE: Would you be interested in receiving this information before your care plan? PROBE: Would you want more information to take home? Further conversation?</p> <p>Q. In your own words, how would you describe this person-centered care planning process to a friend or family member?</p> <p>Q. How do you think this process might affect your dialysis care?</p>

Cognitive Interview Care Provider (Clinic Personnel and Medical Provider) Interview Guide

1. Welcome	
2. Ground Rules	

3. Introduction	
4. Overall impression and general thoughts	<p>Q. What was your overall impression of the materials?</p> <p>Q. What was it like to read the materials? PROBE: How did you feel about the length?</p> <p>Q. What did you think of the different sections? PROBE: How does the information flow? PROBE: What, if anything would you change about the layout? Formatting?</p>
5. Section by section materials review	<p>Q. What did you think about [XX] section? PROBE: Which is the most helpful part of this section? PROBE: Was anything confusing? Unclear? Misleading? Missing? PROBE: What other information would be helpful to include?</p> <p>Q. After reading the description, how would you describe “person-centered dialysis care planning” in your own words? PROBE: How can the definition/explanation be made clearer?</p> <p>Q. What did you think about the figure at the bottom of page 1? PROBE: What does “problem-based” mean to you? PROBE: What does “priority-based” mean to you? PROBE: Is anything confusing? Unclear? Misleading? Missing?</p> <p>Q. What did you think about the evidence of this process being used in other populations? PROBE: Is this information helpful to include? PROBE: Would you be interested in this section having more information? If yes, what kind(s) of information? If no, why not?</p> <p>Q. What did you think about care planning process description? PROBE: How could we describe the process more clearly?</p> <p>Q. What did you think about the conversation guide? PROBE: Would this guide help you facilitate a person-centered care plan meeting? If yes, how? If no, why? PROBE: What do you think about the example questions? PROBE: What tips might be helpful to include?</p>
6. Perspectives on implementation	<p>Q. What did you think about the priorities, barriers, and care plan actions? PROBE: What did you think of the three-column format? PROBE: Which example(s) resonated with you most?</p> <p>Q. What did you think about the potential challenges & solutions? PROBE: Which example(s) resonated with you most? PROBE: Are there key challenges that were not included? If so, what are they?</p> <p>Q. What are your overall impressions of person-centered dialysis care planning? PROBE: What are some strengths of this approach? Weaknesses?</p> <p>Q. How could this care planning process could affect your patients’ dialysis care?</p> <p>Q. How feasible do you think it is to implement person-centered dialysis care planning? PROBE: What challenges would you expect? PROBE: Which components do you see as most feasible? Least feasible? PROBE: What are some strategies to increase the likelihood of implementation?</p> <p>Q24. How willing would you be to incorporate components of person-centered dialysis care planning into your practice?</p>

Supplemental Table 3. Additional illustrative quotations from concept elicitation interview participants.

Themes and subthemes with supporting quotations
Feeling boxed in by the system
<p><u>Checking task-oriented boxes</u> <i>Dietitian:</i> “I feel like it’s more focused on the list of questions that I have for the patient but it’s not – at least for my part, I’m not really asking them what they’re [patients are] concerned about.” <i>Social worker:</i> “Sometimes I think out of sight out of mind you just get into a routine and you just do it to do it and move forward.” <i>Medical provider:</i> “You know, they’re treating the number and not the patient, and I think the patients pick up on that.”</p> <p><u>Surrendering to the weight of the system</u> <i>Patient:</i> “...and then the day about gone and [the doctors] are trying to fly through you, and now your idea of what you had intended to ask the doctor is gone.” <i>Nurse:</i> “I think that [labs are] blanket goals that become the patient goals because that’s how we are scored and reviewed, so of course we are wanting to make those their goals because that’s how it reflects on us as caretakers.” <i>Medical provider:</i> “So I guess I would say to a large degree [care plan meetings] are a waste of everyone’s time in their current format.”</p> <p><u>Being influenced by historical experiences</u> <i>Patient:</i> “They’re going to do what they want to do anyway. I mean it made me feel like my point of view ain’t [matter] no one listens.” <i>Medical provider:</i> “I think some patients really do take it seriously, and they do get really upset when they feel like it’s kind of been shirked or cut short or they don’t really get to say anything.”</p>
Navigating dual lives
<p><u>Experiencing isolation</u> <i>Nurse:</i> “...a lot of times the patient’s families do not get to see what the patient goes through day-to-day with dialysis and how it really is a big deal. It’s a big treatment. These needles and the blood and the time.”</p> <p><u>Making trade-offs</u> <i>Patient:</i> “I still like to try to have some kind of lifestyle, and dialysis really interferes with my lifestyle the way I would like it. I can do it on a minimum and that’s aggravating to me. I just hate being – feeling like I’m locked down, and then dialysis three days a week makes me feel locked down cause I can’t do what I want to do.”</p>
Acknowledging an evolving identity
<p><i>Patient:</i> “[Dialysis] don’t stop me from doing what I want, but see I just don’t do what I used to do.” <i>Patient:</i> “I’m to the point now if there’s something that I really, really want to do, I’ll find a way to get it done.” <i>Medical provider:</i> “[Dialysis] is taking 12 hours a week from these people, and that’s 12 hours that they have no control. We’re entirely in control of their lives and I think that can be kind of demoralizing to an extent.”</p>
Respecting the individual as a whole person
<p><i>Nurse:</i> “...we all need guidelines to say this is what we need to go by in order to provide you an excellent treatment. On the other side of that, on a personal level of quality care, I think quality care is being involved with the patient. ‘Hey, how’s it going?’ ‘You look pretty today.’ ‘How are those grandkids?’ Getting down to that person.” <i>Social worker:</i> “I think it would add a whole lot if a physician said, ‘hey, tell me about church, I heard you went to church finally, like that’s great.’ Or, ‘hey, I heard you went out on the golf course, how was it?’...those would make huge impacts on a patient and the relationship they have with a physician, and feeling like they were more than just a dialysis patient.”</p>
Increasing individualization to enhance care
<p><i>Patient:</i> “So when he knows you personally like that, that’s the type of person I want working with me because that means...well, they care.” <i>Dietician:</i> “...even just having things explained from different points of view I think can help...maybe the doctor can jump in and give more of the medical explanation or background to why something might be happening and then [the social worker] can jump in and give more social references or ask appropriate questions for [that] field. I think it does help to address one [patient] issue from both sides when everyone is there.” <i>Medical provider:</i> “And what we end up doing unfortunately is the part that’s the easiest. You can make the Kt/V whatever you want it. You can make the potassium usually whatever you want it. You can feed them protein. But none of that is the patient’s goal, I don’t think, or very rarely.” <i>Medical provider:</i> “But I think that’d work if you sort of let the patient verbalize what they want and what they’re expecting, and not us [providers] telling them what we expect.”</p>

Supplemental Table 4. Perspectives on terminology for capturing patient priorities and example responses.

Question	Elicited Perspectives	Example Responses
<p>What are some of your life goals?</p>	<ul style="list-style-type: none"> • Lofty and potentially unattainable <ul style="list-style-type: none"> ○ <i>Patient:</i> “The sky’s the limit as far as reaching out for stuff.” • Values and morals <ul style="list-style-type: none"> ○ <i>Patient:</i> “To me that’s a full life, you know, loving, receiving love, giving love, helping others.” ○ <i>Patient:</i> “To encourage other dialysis patients, coming back, talking to them, encouraging them to hold on, to endure, and take care of themselves and just keep believing...” • Distant future <ul style="list-style-type: none"> ○ <i>Patient:</i> “...just living to see my grandkids graduate and what they’re going to do with their life...” 	<ul style="list-style-type: none"> • To stop dialysis • To live, to be happy • To win the lottery • To use the bathroom more • To play professional football • To have more money • To not burden my family • “I have none...it’s like I don’t care no more, I’m hopeless.”
<p>What are some of your goals?</p>	<ul style="list-style-type: none"> • Laboratory value based and health-related <ul style="list-style-type: none"> ○ <i>Patient:</i> “[You mean] the goal on the machine...make sure it ain’t pulling too fast?” ○ <i>Patient:</i> “[The report card] will show you what goals you’re reaching and what you’re not reaching.” ○ <i>Nurse:</i> “Like we gave them a goal to get their phosphorus within range, for example...” ○ <i>Physician:</i> “I always think of end-of-life goals.” 	<ul style="list-style-type: none"> • Getting my blood clean • Getting my phosphorous right • Eating the right food • Not being over my dry weight • “Nothing right now”
<p>What’s important to you?</p> <p>What matters to you?</p>	<ul style="list-style-type: none"> • Easily recalled and identified <ul style="list-style-type: none"> ○ <i>Patient:</i> “It’s on my mind all the time.” • Personal needs and priorities <ul style="list-style-type: none"> ○ <i>Patient:</i> “It’s something I’m trying to do and I’m going to try my best to reach.” • Shorter-term and actionable <ul style="list-style-type: none"> ○ <i>Patient:</i> “You all could help it change.” ○ <i>Nurse:</i> “Let’s try to do just small steps, whatever it might be. Getting back to doing something you really enjoy or like.” <p><u>Example dialogue from a single interview</u> <i>Interviewer:</i> “What kind of goals do you have now?” <i>Patient:</i> “None.” <i>Interviewer:</i> “Okay, well...talk to me about what’s important in your life.” <i>Patient:</i> I just wish I could go back to work...I would look forward to getting up in the morning and go to work and come back and fix my son’s dinner and stuff...”</p>	<ul style="list-style-type: none"> • Working • Fishing • Spending time with family • Receiving a transplant • Traveling • Being active • Volunteering • Housekeeping • Cooking • Visiting friends • Finishing school • Driving • Golfing



MY DIALYSIS PLAN

Program Materials

- A. Patient Brochure
- B. Care Team Brochure
- C. Pre-Meeting Questionnaire
- D. Care Plan with Action Steps and Follow-Up

Complete materials available at: go.unc.edu/mydialysisplan



MY
DIALYSIS
PLAN™

YOUR CARE PLAN MEETING IS COMING UP!

During this meeting, you and your care team will work together to make decisions about your health, well-being, and dialysis care. This brochure explains what to expect and how to prepare.

Your dialysis care plan should be made just for you!





YOUR DIALYSIS CARE PLAN SHOULD BE LIKE A MAP TO HELP YOU GET YOU WHERE YOU WANT TO BE.

It should be unique to your needs and priorities.
It should reflect what matters most to you!

IMPORTANT: CONFIDENTIALITY

Your care team will keep your health information safe and private. Your dialysis care plan is part of your confidential medical record.

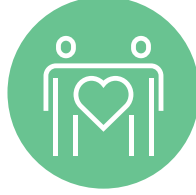


WHAT IS IT?

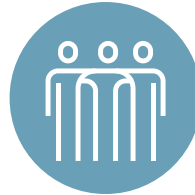
For most patients, care plan meetings happen once a year. Usually, the meeting will include you, a social worker, dietician, doctor, and nurse. You can also invite a family member or friend.



You



Family Member



Friend



Social Worker



Dietician



Kidney Doctor



Nurse

During the meeting, you and your care team might discuss things like lab results, transplant options, or how well you feel on dialysis. It is also helpful to talk about what matters to you in life outside of dialysis. This information is used to make a dialysis care plan to improve your health and well-being.



WHAT IS THE CARE PLAN MEETING LIKE?

- Usually, the meeting will include you, a social worker, dietician, doctor, and nurse.
- You are encouraged to invite a family member, care partner, or friend to join the meeting.
- Everyone will have a chance to share their thoughts, ask questions, help make decisions, or just listen and learn.
- You and your care team will work together to make a plan that meets your needs and priorities.
- Your care team will take notes and review them with you at the end of the meeting.
- You will receive a copy of your care plan to take home.



At the end, everyone should agree on what to do, how to do it, and when to follow-up. This information goes into your dialysis care plan.



WHAT DO I DO DURING THE CARE PLAN MEETING?

- Don't be shy! Speak up! Your voice matters.
- Ask questions about anything you don't understand.
- If you need help, ask for it.
- Work with your care team to figure out how to get where you want to be.
- If you want to talk more with someone on your team after the meeting, just let them know!

“

“It’s a meeting where you can express yourself about your dialysis and how it’s going. A time to not feel bad about talking to someone about your personal problem... also a way to help you achieve some of your goals.” – Patient



HOW DOES CARE PLANNING WORK?

STEP 1 Prepare for the meeting

You and **your care team** each have a part.

You prepare by thinking about what you need for your health and well-being.



Your care team prepares by reviewing your dialysis care.

“

“The more the care team knows about you, the more the care plan is individually catered to you, because everybody’s different.” – Patient



THINK ABOUT THE QUESTIONS BELOW...

These might come up during your care plan meeting. You can ask your family, friends, or care partner for help or ideas.

- ▶ What matters to you?
- ▶ What does a good day look like for you?
- ▶ What changes do you want to see in your life?
- ▶ What would you like to be able to do that you can't do now?
- ▶ What questions or concerns do you have about dialysis or your care?



STEP 2 Meet with your care team

- During your care plan meeting, you'll be able to tell your care team what is important to you.
- Sharing what matters to you helps your care team understand you as a person.

For example, you might want to:



Travel more



Learn something new



Be able to get around better



Spend more time with family or friends

- You and your care team will work together to design a dialysis care plan that matches your needs and priorities.



STEP 3 Keep talking with your care team!

- If your dialysis care plan doesn't feel right or you think something should change, you can always talk to a care team member.
- You don't have to wait for another care plan meeting. Feel free to ask questions any time.
- Your care team will check-in to see if your care plan is meeting your needs.

“

“This is your life and your life is in the hands of other people...it's your body! Talk it out!” – Patient



MORE INFORMATION

If you want to learn more, ask your care team for more information!



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MY
DIALYSIS
PLAN™

My Dialysis Plan™, also known as person-centered care planning, helps care teams align dialysis care with patient needs and priorities. The goal of My Dialysis Plan™ is to improve patient health through increased communication, shared decision-making, and close follow-up.





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- 4 Approach

Tools and Resources

- 5 Step-by-step conversation guide for the care plan meeting
- 6 Examples of patient priorities, barriers, and possible care plan actions
- 7 Potential challenges and solutions

OVERVIEW

Person-centered dialysis care planning aligns care with what matters most to individual patients. My Dialysis Plan™ aims to shift care planning from a problem-based approach to a priority-based approach.

Key program components:

- Learn about patient priorities and challenges to achieving personal goals
- Engage in shared decision-making to create an action plan
- Follow up and reevaluate patient priorities and challenges over time

Key program outcomes:

- Individualized care plans that help patients achieve their personal goals and better health
 - Greater trust and satisfaction among patients and care teams
-

Person-centered care planning is a collaborative process in which patient-identified needs and priorities guide health care decision-making and inform development of an individualized plan of care.

In dialysis care planning, this involves linking patient-identified priorities to care plan components like bone-mineral disease, anemia, pain management, among others. By collaborating as equal partners, the patient and care team agree upon action steps to reach identified goals, establish benchmarks for progress, and outline plans for follow-up.



In the end, **the care plan should be a personalized map** to help patients achieve their personal goals and get where they want to be.



Current Approach

PROBLEM-BASED

- Step 1 Review the same generic, unprioritized problem list with all patients.
- Step 2 Discuss all problems whether they are important to patients or not.
- Step 3 **END** care plan meeting without follow-up plans and often without asking about patient priorities.

Care Planning Paradigm Shift

My Dialysis Plan™

PRIORITY-BASED

- Step 1 **START** care plan meeting by asking about patient priorities.
- Step 2 Discuss challenges associated with patient-identified priorities and any remaining care team concerns.
- Step 3 Work with patients to make care decisions and prepare follow-up plans.

EVIDENCE SUPPORTING THIS APPROACH^{a,b,c}

Studies have shown that person-centered (or individualized) care planning:

- Enhances patient experiences and provides a more meaningful context to care
- Promotes patient engagement and self-efficacy
- Improves clinical outcomes
- Improves teamwork and increases care team satisfaction
- Creates shared responsibility between patients and care teams

a. Mold, J. (2017). Goal-Directed Health Care: Redefining Health and Health Care in the Era of Value-Based Care. *Cureus*, 1043.

b. Pirhonen, L., Olofsson, E. H., Fors, A., Ekman, I., & Bolin, K. (2017). Effects of person-centred care on health outcomes — A randomized controlled trial in patients with acute coronary syndrome. *Health Policy*, 121(2), 169–179.

c. Pol-Grevelink, A., Jukema, J., & Smits, C. (2011). Person-centred care and job satisfaction of caregivers in nursing homes: A systematic review of the impact of different forms of person-centred care on various dimensions of job satisfaction. *International Journal of Geriatric Psychiatry*, 27(3), 219–229.

THE CARE PLANNING APPROACH

Person-centered dialysis care planning involves some preparation:

- Invite patients to participate and identify their preferences for meeting time, location, and guests.
- Schedule care plan meetings according to patient preferences and notify care team members of care plan meetings in advance.
- At least one week prior to the meeting, share the care planning video and brochure with patients so they have an opportunity to prepare.
- Before meeting with the patient, huddle with the care team to discuss assessments and relevant information.
- Use the step-by-step conversation guide to elicit patient needs and priorities during the care plan meeting and develop an individualized care plan.



Be patient during this process as it may feel unfamiliar initially.

STEP-BY-STEP CONVERSATION GUIDE FOR THE CARE PLAN MEETING

Step 1.

Ask open-ended questions about the patient's life such as...

- ▶ What kinds of things do you do on a typical day? What about on a non-dialysis day?
- ▶ What does a good day look like for you?
- ▶ What is important to you? What matters to you?
- ▶ What would you be doing if you weren't on dialysis?
- ▶ What would you like to be able to do that you can't do now?

Step 2.

Clarify by asking for additional information, if needed.

- ▶ Could you tell me more about that?
- ▶ What do you mean by that?

Step 3.

Identify any barriers that may exist for the patient by asking...

- ▶ What is getting in the way of that?
- ▶ How does dialysis influence that?

Step 4.

Work with the patient to prioritize their identified needs. Use questions such as...

- ▶ What would you like to focus on now?
- ▶ What do you see as the next steps to get you there?
- ▶ What things would you like to address in the long-term?

Step 5.

Develop a care plan through shared decision-making, designating who is responsible for each action item. Ask questions like...

- ▶ How can we help you with that?
- ▶ What do you need to make this happen?
- ▶ What do you think would work for you?

Step 6.

Summarize the care plan at the end of the meeting to ensure accurate understanding and interpretation by everyone.

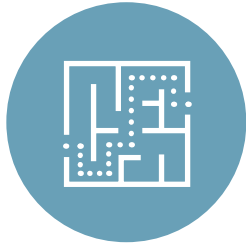
Step 7.

Give the patient a copy of the care plan to take home.



- **Make time and space for questions.**
- **Take notes during the meeting, rather than afterward.**
- **Ask if there is anything else to discuss before closing.**

EXAMPLES OF PATIENT PRIORITIES, BARRIERS, AND POSSIBLE CARE PLAN ACTIONS



Sometimes, patient priorities may seem out of scope or unrelated to dialysis. However, there are often creative ways to align the dialysis care plan with patient priorities.

PATIENT PRIORITY	POTENTIAL BARRIER	POSSIBLE CARE PLAN ACTIONS
Get on the transplant list	Ineligible due to frail status and comorbid disease burden	<ul style="list-style-type: none"> Refer to physical therapy for an exercise program for strengthening. Refer to a primary care clinician for better management of comorbidities. Refer to another transplant center for repeat evaluation.
Shorten dialysis treatment time	Large interdialytic weight gains	<ul style="list-style-type: none"> Identify action steps for diet and lifestyle modifications. Establish a timeline for completion and follow-up. Designate a time to assess progress and reevaluate patient priorities.
Spend more time with grandchildren	Long recovery time because of post-dialysis fatigue	<ul style="list-style-type: none"> Perform a time-limited trial of shorter dialysis or nocturnal dialysis (if available). Conduct formal time to recovery assessments weekly to see if post-dialysis fatigue improves.
Homeschool children	In-center, thrice weekly treatment	<ul style="list-style-type: none"> Discuss options like nocturnal dialysis (if available), home dialysis, and peritoneal dialysis.
Maintain work as a part-time employee with an irregular work schedule	Tuesday, Thursday, Saturday treatment schedule interferes with inconsistent work shifts	<ul style="list-style-type: none"> Modify treatment schedule to allow for consistent Saturday work shifts to maintain part-time status. Elect a care team member to review the monthly work schedule with the patient to determine other helpful changes.



POTENTIAL CHALLENGES AND SOLUTIONS

There may be some challenges with implementing person-centered care planning. Often, these can be resolved with strategic planning, patient empowerment, and transparent communication.

POTENTIAL CHALLENGE	POTENTIAL SOLUTIONS
Past experiences with care planning may influence patients' communication and/or willingness to participate.	<ul style="list-style-type: none">• Empower patients with preparation materials (video and brochure), and answer their questions.• Explain how this approach may improve their dialysis experience.• Schedule the meeting in alignment with patient preferences (location, timing, guests) to demonstrate that you are listening.
Each day is already busy, so it may be difficult to balance care team responsibilities with additional patient follow-up.	<ul style="list-style-type: none">• Establish a follow-up plan collaboratively with patients and work together to delegate action items among care team members and patients.• Encourage patients to follow up with the care team. <p>For Example A patient may be interested in more frequent follow-up, which may best be performed by a clinic staff member rather than a medical provider.</p>
It may feel overwhelming to imagine this approach in bigger clinics.	<ul style="list-style-type: none">• Stagger care plan meetings evenly over the year, even if some are performed before their annual due dates.• Review the calendar in advance to prevent scheduling conflicts and facilitate entire care team involvement.
Patient priorities may conflict with traditional care plans. For Example Patients may want shorter treatment time to get home earlier to see family. However, shortening treatments may lead to inadequate clearance and/or fluid balance.	<ul style="list-style-type: none">• Provide education and offer choices.• Use shared decision-making.• Incorporate care trade-off discussions. <p>For Example If care teams explain that shortening treatment time may be detrimental for other reasons (faster fluid removal and potentially greater fatigue), the patient may request information about other options to maximize quality time at home.</p>



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C. Pre-Meeting Questionnaire



MY DIALYSIS PLAN™

PRE-MEETING QUESTIONNAIRE

Some people find it helpful to have family or a care partner join the meeting. They can ask questions and help you make decisions, or just listen and learn.

Would you like to invite someone to your care plan meeting?

Yes No

Who would you like to invite?

Name _____

Relationship _____

Contact information _____

Meetings off the treatment floor can help everyone focus better.
This also helps keep your information private.

Where would you like your meeting to occur?

- Private space off the treatment floor
 Over the phone (phone number _____)
 On the treatment floor

When would you like your meeting to occur?

- Before treatment
 During treatment (only for meeting occurring on the treatment floor)
 After treatment
 Off-day

Do you need assistance with transportation?

Yes No

Details: _____

PATIENT NAME _____

PATIENT SIGNATURE _____

DATE _____

NOTES

D. Care Plan with Action Steps and Follow-Up



MY DIALYSIS PLAN™

PATIENT: _____ NOTE-TAKER: _____

MEETING ATTENDEES: _____

LOCATION: private chairside other: _____ DATE: _____

WHAT IS IMPORTANT? WHAT MATTERS? (prioritized with patient)

Patient-identified needs & priorities

- _____
- _____
- _____

WHAT ARE SOME CHALLENGES? (identified by patient and/or care team member)

Barriers to accomplishing the above

- _____
- _____
- _____

WHAT ARE THE NEXT STEPS? (agreed upon by all)

Care team steps & responsible party

Time frame

1. _____
2. _____
3. _____

Patient steps

Time frame

1. _____
2. _____
3. _____

ADDITIONAL INFORMATION



FOLLOW-UP

Date & time: _____

Name(s) of care team member(s): _____

Notes (information shared, decisions made, care plan modifications, etc.)

FOLLOW-UP

Date & time: _____

Name(s) of care team member(s): _____

Notes (information shared, decisions made, care plan modifications, etc.)

FOLLOW-UP

Date & time: _____

Name(s) of care team member(s): _____

Notes (information shared, decisions made, care plan modifications, etc.)
