Supplementary data

Table 1. List of experts participating in the content validity assessment

No	Service organization	Job title / Position / Title
1	Taichung veteran general hospital	Attending Physician in the Palliative Care Department of the Family Medicine Division
2	Taichung veteran general hospital	Deputy Head Nurse of the Hemodialysis Unit
3	Taichung veteran general hospital	Director of Palliative Care Unit
4	WelGong Memorial Hospital	Attending Physician in Nephrology Department and Director of Peritoneal Dialysis Unit
5	Taichung veteran general hospital	Director of Palliative Care Unit in the Family Medicine Department
6	Department of Healthcare Administration in Asia University	Associate Professor
7	Taichung veteran general hospital	Director of Nursing Department (Overseeing Palliative Care Unit)
8	Taichung veteran general hospital	Head of Nephrology Department
9	Ditmanson Medical Foundation Chia-Yi Christian Hospital	Director of Nursing Department (Overseeing Dialysis Services)
10	Taichung veteran general hospital	Head Nurse of Palliative Care Unit
11	Department of Healthcare Administration in Central Taiwan University of Science and Technology	Associate Professor
12	Taichung veteran general hospital	Former Director of Palliative Care Unit

Table 2. Operational Definition of Patient Basic Characteristics

Independent variable	Operational definition	types
Demographic		
Gender	Male or female	Categorical
Age	Age while recruitment	Continuous
Level of education	"Below Junior High School," "Junior High School," "Senior High School / Vocational School," "Junior College," "University," "Graduate School and Above"	Categorical
marriage	"Married," "Single," "Divorced, Separated," "Widowed," "Other"	Categorical
Religious Belief	"No Religion," "Chinese Folk Religion," "Buddhism," "Taoism," "Catholicism," "Christianity," "Other"	Categorical
Residential Status	"Living Alone," "Living with Family," "Living with Others"	Categorical
Residential Status	"Work income is sufficient to support" "Savings or retirement are sufficient to support" "Depend on family or friends for support" "Depend on social assistance for support"	Categorical
Comorbidity	"Hypertension" ,"Cardiovascular disease" ,"Diabetes" ,"Heart failure" ,"Ischemic heart disease" ,"Dyslipidemia" ,"Peptic ulcer" ,"Stroke" ,"Arrhythmia", "Chronic Obstructive Pulmonary Disease (COPD)", "Cancer", "Other"	Categorical
Information of dialysis		
Vintage of dialysis	Times in years	Continuous
Why did you choose current dialysis model	"Physician's Wishes," "Personal Wishes," "Family's Wishes"	Categorical
Do you regret the decision for dialysis?	Yes or no	Categorical
Other associated experience		
Have you signed a Do-Not-Resuscitate (DNR) form or an Advance Care Planning (ACP) and Advance Directive (AD) form for palliative care and life-sustaining treatment decisions?	Yes or no	Categorical
Have you had discussions with a physician or healthcare personnel regarding the prognosis and estimated survival time for dialysis?	Yes or no	Categorical
Have healthcare providers discussed with you and your family about medical decisions for dialysis treatment during end-of-life care?	Yes or no	Categorical

Have physicians or healthcare providers provided information to you and your family about Advance Care Planning (ACP) and Advance Directive (AD) for medical decision-making?	Yes or no	Categorical

Table 3. Operational Definition of Other Related Questions

Independent variable	Operational definition	types
Who do you "most" want to discuss your end-of-life wishes with?	"No one", "Nephrologist", "Palliative care physician", "Other specialist physician", "Dialysis nurse", "Palliative care nurse", "Spouse", "Children", "Siblings", "Friends", "Other"	Categorical
When do you "most" prefer to have Advance Care Planning (ACP)?	"When in good health", "When discovering decreased kidney function", "When kidney function deteriorates to require dialysis", "When other severe complications begin to appear", "When in a life-threatening situation"	Categorical
Who do you think "most" should initiate the ACP process?	"The patient themselves," "Nephrologist," "Palliative care physician," "Other specialist physician," "Dialysis nurse," "Palliative care nurse," "Close family members," "Others"	Categorical
Whom would you like to designate as your appointed agent?	"Spouse," "Children," "Siblings," "Friends," "Lawyer," "Others"	Categorical
How much are you willing to self-fund for participating in Advance Care Planning (ACP)?	「33」、「66」、「99」、「132」、「165」、「197」、「263、「328」 US dollars	Categorical
Who do you think should bear the cost of "Advance Care Planning fees"?	"Self-pay in full," "Fully covered by National Health Insurance," "Fully subsidized by the government," "Fully covered by a charitable foundation," "Shared equally between myself and other relevant parties"	Categorical

Table 4. Detailed information of this questionnaire

The first section (baseline data)	For ths first section, we inclued the following variables: demographic variables (gender, age, education level, marital status, religious beliefs, living situation, economic status, other significant illnesses), dialysis treatment details (duration of undergoing dialysis treatment, reasons for choosing the current dialysis method, and any regrets regarding the dialysis decision), experiences related to ACP (whether the participant has previously signed a Do-Not-Resuscitate (DNR) order or an Advance Directive for Palliative and Life-Sustaining Treatment, whether a physician or healthcare provider has discussed prognosis and anticipated survival time related to dialysis, medical decisions regarding dialysis treatment during end-of-life, and information about ACP and AD.
The second section (knowledge)	For ths second section (knowledge), we employs a binary scoring method with a total of 10 questions. Participants are required to mark 'Yes' based on their own perceptions."
The third section (altitute)	In the attitude section, there are four dimensions, including the goals of Advance Care Planning (ACP) and Advance Directives (AD), obstacles to ACP and AD, and patients' autonomy rights. This section comprises a total of 41 items, assessed using a Likert Scale five-point system. Respondents are to indicate their agreement based on their experiences and perceptions, with 'Strongly Agree' being assigned 5 points, 'Agree' - 4 points, 'Neutral' - 3 points, 'Disagree' - 2 points, and 'Strongly Disagree' - 1 point. The total score ranges from 41 to 205, with higher scores indicating a more positive attitude.

	The other part involves importance and consists of 10 items, also assessed using a Likert Scale five-point system. Participants are asked to indicate the importance according to their feelings, with 'Very Important' assigned 5 points, 'Important' - 4 points, 'Neutral' - 3 points, 'Not Important' - 2 points, and 'Not at All Important' - 1 point. The total score ranges from 10 to 50, with higher scores indicating greater importance."
The fourth section (willingness)	In the willingness section (fourth section), there are two dimensions, including willingness to participate and willingness to sign, as well as willingness to maintain life-sustaining treatment. This section consists of a total of 12 items, assessed using a Likert Scale five-point system. Respondents are asked to indicate their willingness, with 'Very Willing' assigned 4 points, 'Willing' - 3 points, 'Unwilling' - 2 points, and 'Very Unwilling' - 1 point. The total score ranges from 12 to 48, with higher scores indicating a higher level of willingness.
The fifth section	In the fifth section, This includes questions such as: "Who would you most like to discuss your end-of-life wishes with?" "When would you prefer to engage in Advance Care Planning (ACP)?" "In your opinion, who should initiate Advance Care Planning (ACP)?" "Whom would you like to designate as your surrogate decision-maker?" "How much would you be willing to pay out of pocket to participate in Advance Care Planning (ACP)?" "In your view, who should be responsible for covering the cost of Advance Care Planning (ACP)?"

Table 5. Complete Questionnaire Content (translate into English)

Questionnaire on Knowledge, Attitudes, and Preferences of Hemodialysis Patients towards Advance Care Planning and Patient Autonomy Rights

"Dear Kidney Patient,

Greetings! We are a research team from the Nephrology Department of Taichung Veterans General Hospital and the Health Care Administration Department of Chung-Tai University of Science and Technology. We are currently conducting a study titled 'Knowledge, Attitudes, and Preferences of End-Stage Renal Disease Patients towards Advance Care Planning and Patient Autonomy Rights.' Your valuable input will help us understand the intentions of end-stage renal disease patients and their families regarding advance care planning and patient autonomy rights. This study aims to provide insights for future reference in matters related to advance care planning and patient autonomy rights.

(Before completing the questionnaire, please read the provided glossary for detailed explanations.)

This questionnaire is designed to be completed anonymously. All collected data will be used solely for academic research and analysis purposes. Your responses will be kept confidential and will not be disclosed to external parties. Your participation is highly appreciated.

Thank you!"

Taichung Veterans General Hospital
Department of Nephrology
Director: Dr. Chen Cheng-Hsu
Chung-Tai University of Science and Technology
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Glossary

- Life-sustaining treatment: Refers to any necessary medical interventions, such as cardiopulmonary resuscitation (CPR), mechanical life-support systems, blood products, specialized treatments for specific diseases, and administration of antibiotics during severe infections, which have the potential to prolong a patient's life.
- Artificial nutrition and hydration: Refers to the provision of food and fluids through tubes or other invasive methods.
- Advance Care Planning (ACP): Refers to the communication process between patients, healthcare providers, family members, or other relevant individuals. It involves discussing appropriate care options for a patient when they are in specific clinical conditions, unconscious, or unable to express their wishes clearly. This includes decisions about life-sustaining treatment and artificial nutrition and hydration that the patient can accept or refuse.
-
- Advance Directive (AD): Refers to a pre-established written statement indicating

a person's preferences for receiving or refusing life-sustaining treatment, artificial nutrition and hydration, or other relevant decisions related to medical care, end-of-life wishes, etc., for specific clinical conditions.

- Medical Surrogate Decision-Maker: Refers to a person designated in writing by an individual to express their wishes when the individual is unconscious or unable to communicate their wishes.
- Specific Clinical Conditions: Refers to meeting one of the following clinical conditions: 1) Terminal illness; 2) Irreversible coma; 3) Permanent vegetative state; 4) Profound dementia; 5) Other diseases or conditions announced by the central competent authority, characterized by unbearable suffering or lack of available treatment options according to the prevailing medical standards.
- End of life: Refers to the point when various medical interventions can no longer cure or control the progression of a disease.

Session 1. Background Information

1. Gender：
   □male □female
2. Age：
3. Educational level：
4. □ Elementary school or below □ Junior high school □ High school/vocational school □ Junior college □ University □ Postgraduate"
5. Marriage：
6. □ Married □ Single □ Divorced, Separated □ Widowed □ Other 宗教信仰：
7. Living Situation:
   □ Living alone □ Living with family □ Living with others"
8. Economic Situation:
   □ Sufficient income from work □ Sufficient savings or retirement funds □ Dependence on family and friends for support □ Dependence on social assistance for support"
9. Do you currently have any other significant illnesses? (Select all that apply)
   □ Hypertension □ Cardiovascular disease □ Diabetes □ Heart failure □ Ischemic heart disease □ Blood lipid abnormalities
   □ Peptic ulcer □ Stroke □ Arrhythmia □ Chronic obstructive pulmonary disease □ Cancer □ Other: _____
10. The dialysis method you currently use:
    □ Peritoneal Dialysis (□ APD □ CAPD □ APD+CAPD)
    □ Hemodialysis (□ 2 times a week □ 3 times a week)
    □ Mixed Peritoneal and Hemodialysis
11. Duration of receiving dialysis treatment: Since the year _____ of the Republic of China
12. What is the primary reason for choosing your current dialysis method?
□ Physician's recommendation □ Personal preference □ Family's expectation
13. Have you (ever) worked in a medical-related occupation?
□ Yes □ No
14. Do you have doubts about your current dialysis decision?□ Yes □ No
15. Have you signed a Do-Not-Resuscitate (DNR) order or an Advance Directive for Palliative and Life-Sustaining Treatment?
    □ Yes □ No
16. Have healthcare professionals discussed the prognosis and expected survival time of dialysis with you and your family?

□ Yes □ No

17. Have healthcare professionals discussed medical decisions in case your condition worsens and becomes life-threatening with you or your family?
    □ Yes □ No
18. Have healthcare professionals provided you or your family with information about Advance Care Planning (ACP) and Advance Directives (AD)?
    □ Yes □ No
19. Have you ever discussed medical decisions in case your condition worsens and becomes life-threatening with your family?
    □ Yes □ No"

Session 2、Knowledge of Advance Care Planning (ACP) and Patient Autonomy Rights

"Please provide your responses to the following items regarding your 'Knowledge of Advance Care Planning (ACP) and Patient Autonomy Rights.' Please select the appropriate option that best matches your level of understanding based on the item descriptions (please place a X inside the □ box that you find suitable)."	Yes	No
1. Have you heard of Advance Care Planning (ACP) before today	□	□
2. Have you heard of Advance Directives (AD) before today?	□	□
3. Did you know that you can designate a medical surrogate decision-maker to express your medical wishes when you are unconscious or unable to communicate your preferences?	□	□
4. Are you aware that Taiwan began implementing the Patient Autonomy Act in 2019 (Republic of China year 108)?	□	□
5. Are you aware that under the Patient Autonomy Act, patients can sign an Advance Directive (AD) to decide in advance the treatment they wish to receive or refuse at the end of life?	□	□
6. Are you aware that under the Patient Autonomy Act, healthcare providers can provide treatment according to a patient's Advance Directive if the patient is unable to make decisions themselves?	□	□
7. Are you aware that under the Patient Autonomy Act, patients can appoint a medical surrogate decision-maker to make treatment decisions on their behalf when they cannot make decisions themselves?	□	□
8. Are you aware that even after signing an Advance Directive (AD), you can still change your initial decision?	□	□
9. Are you aware that you can have more than one medical surrogate decision-maker?"	□	□
"Please provide your responses to the following items regarding your 'Knowledge of Advance Care Planning (ACP) and Patient Autonomy Rights.' Please select the appropriate option that best matches your level of understanding based on the item descriptions (please place a X nside the □ box that you find suitable)."	Yes	No
10. Are you aware that after signing an Advance Directive (AD), it needs to be recorded on the National Health Insurance IC Card to become effective?"	□	□

Session 3. Attitudes towards Advance Care Planning (ACP) and Patient Autonomy Rights

Please provide your responses to the following items regarding your 'Knowledge of Advance Care Planning (ACP) and Patient Autonomy Rights.' Please choose the appropriate option that best matches your level of understanding based on the item descriptions (please place a X inside the □ box that you find suitable	Strongly agree	Agree	No opinion	Disagree	Strongly disagree
1. Advance Care Planning (ACP) can help you understand the various available care options at the end of life, along with their benefits and risks.	□	□	□	□	□
2. ACP can enhance the understanding of your values and preferences in end-of-life care for both your family and healthcare team, leading to consensus building.	□	□	□	□	□
3. ACP can reduce the likelihood of receiving ineffective medical treatment at the end of life.	□	□	□	□	□
4. ACP gives you more confidence in facing the worst outcomes of your illness, including death.	□	□	□	□	□
5. ACP can ensure your quality of life at the end of life.	□	□	□	□	□
6. ACP can lessen the psychological burden on your family when making medical decisions on your behalf.	□	□	□	□	□
7. ACP should involve regular discussions, allowing you to review the progress of various relevant medical interventions and whether your preferences need to be updated.	□	□	□	□	□
8. Given the higher risk of death in end-stage kidney disease (uremia) compared to other illnesses, do you think participating in ACP is necessary?	□	□	□	□	□
9. Do you believe that end-stage kidney disease (uremia) patients should begin discussing Advance Care Planning (ACP) in the early stages of dialysis?"	□	□	□	□	□
10. Advance Directives (AD) allow you to make medical decisions for yourself even when you lose decision-making capacity.	□	□	□	□	□
11. Implementing Advance Directives (AD) can reduce unnecessary suffering at the end of life.	□	□	□	□	□

Please provide your responses to the following items regarding your 'Knowledge of Advance Care Planning (ACP) and Patient Autonomy Rights.' Please choose the appropriate option that best matches your level of understanding based on the item descriptions (please place a X inside the □ box that you find suitable	Strongly agree	Agree	No opinion	Disagree	Strongly disagree
12. Advance Directives (AD) enable you to make end-of-life care decisions based on your values and life goals, contributing to a peaceful end of life.	□	□	□	□	□
13. You believe that the appointed healthcare proxy will represent your medical decisions when you're unconscious or unable to express your wishes.	□	□	□	□	□
14. You are not yet ready to discuss Advance Care Planning (ACP).	□	□	□	□	□
15. Discussing Advance Care Planning (ACP) inevitably involves the topic of death, which may make life seem hopeless to you.	□	□	□	□	□
16. You think that doctors or nurses don't have sufficient education to discuss Advance Care Planning (ACP) with you and your family.	□	□	□	□	□
17. You believe that doctors or nurses don't have enough time to discuss Advance Care Planning (ACP) with you and your family.	□	□	□	□	□
18. The process of signing an Advance Directive (AD) involves contemplating death or incapacity, which can be unpleasant.	□	□	□	□	□
19. Signing an Advance Directive (AD) requires a significant amount of time.	□	□	□	□	□
20. If you sign an Advance Directive (AD), you worry about being abandoned by medical treatment.	□	□	□	□	□
21. Signing an Advance Directive (AD) is unnecessary as you trust your loved ones to make the right decisions on your behalf.	□	□	□	□	□
22. You think that even if you sign an Advance Directive (AD), you can't be sure that the medical team will follow your wishes when needed.	□	□	□	□	□

Please provide your responses to the following items regarding your 'Knowledge of Advance Care Planning (ACP) and Patient Autonomy Rights.' Please choose the appropriate option that best matches your level of understanding based on the item descriptions (please place a X inside the □ box that you find suitable	Strongly agree	Agree	No opinion	Disagree	Strongly disagree
23. You're concerned that a signed Advance Directive (AD) may not cover all future medical decisions.	□	□	□	□	□
24. Signing an Advance Directive (AD) makes you fear a reduction in medical care by the healthcare team at the end of your life.	□	□	□	□	□
25. You have signed a Do Not Resuscitate (DNR) order or an Advance Directives for Hospice and Palliative Care, so you don't need to sign an Advance Directive (AD) again.	□	□	□	□	□
26. For you, appointing a healthcare proxy is unnecessary because you don't want to burden your family emotionally.	□	□	□	□	□
27. You don't believe that your current dialysis endangers your life, so you've never considered the issue of death.	□	□	□	□	□
28. You believe that for end-stage kidney disease (uremia) patients, extending life-sustaining treatment is more important than discontinuing life-sustaining treatment.	□	□	□	□	□
29. The Patient Autonomy Act only allows patients to exercise their right to refuse medical treatment, which can lead to natural death, not euthanasia.	□	□	□	□	□
30. Patients have the right to be informed about their condition, treatment options, potential outcomes, and risks, and the right to choose and decide about the treatment options provided by doctors, without interference from others.	□	□	□	□	□
31. During patient visits, the healthcare team should inform the patient or, if the patient does not object, the family or relevant individuals, about the patient's condition, treatment plan, procedures, medications, prognosis, and possible adverse reactions at an appropriate time and in a suitable manner.	□	□	□	□	□

Please provide your responses to the following items regarding your 'Knowledge of Advance Care Planning (ACP) and Patient Autonomy Rights.' Please choose the appropriate option that best matches your level of understanding based on the item descriptions (please place a X inside the □ box that you find suitable	Strongly agree	Agree	No opinion	Disagree	Strongly disagree
32. When engaging in Advance Care Planning (ACP), the patient, at least one immediate family member within the second degree of kinship, and the healthcare proxy must all participate.	□	□	□	□	□
33. Signing an Advance Directive (AD) requires prior Advance Care Planning (ACP) with the healthcare team, institutional endorsement, notarization by a notary public, or witnessing by two or more individuals, and it must be documented on the National Health Insurance (NHI) IC card to be effective.	□	□	□	□	□
34. Even after signing an Advance Directive, you can still withdraw or modify it at any time in writing.	□	□	□	□	□
35. If the patient's most recent medical decision is to receive life-sustaining treatment or artificial nutrition and hydration, doctors should immediately execute the patient's wishes.	□	□	□	□	□
36. If the patient's most recent medical decision is to refuse life-sustaining treatment or artificial nutrition and hydration, doctors should still follow the original Advance Directive until the process of updating the IC card is completed.	□	□	□	□	□
37. The appointed healthcare proxy must be at least twenty years old and possess full legal capacity, and their appointment must be made in writing.	□	□	□	□	□
38. The healthcare proxy, when the patient is unconscious or unable to express their wishes, has the authority to represent the patient's medical decisions, including receiving information from the healthcare team, signing consent forms, and expressing the patient's medical wishes according to the content of the patient's Advance Directives.	□	□	□	□	□

Please provide your responses to the following items regarding your 'Knowledge of Advance Care Planning (ACP) and Patient Autonomy Rights.' Please choose the appropriate option that best matches your level of understanding based on the item descriptions (please place a X inside the □ box that you find suitable	Strongly agree	Agree	No opinion	Disagree	Strongly disagree
39. If there are multiple healthcare proxies appointed, each of them can independently execute the patient's Advance Directives, without requiring all of them to be present.	□	□	□	□	□
40. If a patient meets any of the clinical conditions such as end-stage disease, irreversible coma, permanent vegetative state, severe dementia, and others, and has Advance Directives, the healthcare team can use the patient's Advance Directives to terminate, withdraw, or withhold all or part of life-sustaining treatment or artificial nutrition and hydration."	□	□	□	□	□
41. The healthcare team has the right, based on their expertise or discretion, to not carry out the patient's Advance Directives.	□	□	□	□	□

Session 4. The Importance of Advance Care Planning (ACP) for End-Stage Kidney (Uremia) Patients

Please select the appropriate option (place a X inside the box) based on your perception of the importance of the following items regarding 'The Importance of Advance Care Planning (ACP) and Patient Autonomy Act	Very important	Important	Neut	Not important	Very umimportant
1. Enhancing patients and families' understanding of the illness, including prognosis, treatment options (dialysis treatment, conservative management, and palliative care services), and potential outcomes of these treatment choices.	□	□	□	□	□

2. Guiding patients in establishing care goals, including in scenarios of losing decision-making capacity and during end-of-life situations.	☐	☐	☐	☐	☐
3. Develop care plans in alignment with patients' goals, incorporating their preferences for situations of loss of decision-making capacity, meeting specific clinical conditions, and end-of-life care.	☐	☐	☐	☐	☐
4. Ensure that healthcare professionals make medical decisions in accordance with the patient's Advance Directive (AD) wishes.	☐	☐	☐	☐	☐
5. Assist in maintaining the quality and dignity of life for patients, promoting emotional tranquility.	☐	☐	☐	☐	☐
6. Strengthen opportunities for patients and their loved ones to discuss the patient's future care preferences.	☐	☐	☐	☐	☐
7. Aid in alleviating the emotional burden experienced by patients and their loved ones during medical decision-making.	☐	☐	☐	☐	☐
8. Assist patients in designating healthcare proxy agents for future care decisions.	☐	☐	☐	☐	☐
9. Support healthcare proxy agents in understanding their roles and responsibilities in the patient's future medical decisions.	☐	☐	☐	☐	☐
10. Facilitate mutual understanding among patients, healthcare proxy agents, and healthcare professionals regarding the patient's values and wishes.	☐	☐	☐	☐	☐

Session 5. Willingness towards Advance Care Planning (ACP) and Patient Autonomy Rights

Please choose the appropriate option (place a X □ inside the box) based on your willingness, considering the descriptions provided, regarding "Willingness towards Advance Care Planning (ACP) and Patient Autonomy Act":	Very willing	Willing	Unwilling	Very unwilling
1. Are you willing to participate in Advance Care Planning (ACP)?	□	□	□	□

Please choose the appropriate option (place a X □ inside the box) based on your willingness, considering the descriptions provided, regarding "Willingness towards Advance Care Planning (ACP) and Patient Autonomy Act":	Very willing	Willing	Unwilling	Very unwilling
2. Are you willing to sign an "Advance Directive" (AD)?	□	□	□	□
3. Are you willing to encourage your family members to participate in Advance Care Planning (ACP)?	□	□	□	□
4. Are you willing to encourage your family members to sign an "Advance Directive" (AD)?	□	□	□	□
5. Are you willing to sign a "Do Not Resuscitate (DNR) Order or Advance Care Planning and Life-sustaining Treatment Decision Directive"?	□	□	□	□
6. Are you willing to sign an "Advance Medical Proxy Appointment Directive" to designate a medical proxy?	□	□	□	□
7. Are you willing, under the recommendation of a physician, to reduce or discontinue dialysis during end-of-life or specific clinical conditions?	□	□	□	□
8. If diagnosed with specific clinical conditions, would you be willing to accept enteral feeding through a "nasogastric tube"?	□	□	□	□
9. If diagnosed with specific clinical conditions, would you be willing to accept treatment involving "tracheal intubation"?	□	□	□	□
10. If diagnosed with specific clinical conditions, would you be willing to accept "cardiopulmonary resuscitation" (CPR) measures?	□	□	□	□
11. If diagnosed with specific clinical conditions, would you be willing to accept "emergency medication administration" measures?	□	□	□	□
12. If diagnosed with specific clinical conditions, would you consider stopping or reducing dialysis?	□	□	□	□

Other Related Questions about Advance Care Planning (ACP) and Patient Autonomy Law

1. Who would you "most" like to discuss your end-of-life wishes with? (Choose one)

   □ Don't want to discuss with anyone □ Nephrologist □ Palliative care physician □ Other specialist physician□ Dialysis nurse □ Palliative care nurse □ Spouse □ Children □ Siblings □ Friends

   □ Other_____

2. When would you "most" prefer to undergo Advance Care Planning (ACP)? (Choose one)

□ When I am healthy □ When I notice a decline in kidney function □ When kidney function worsens and requires dialysis □ When other serious complications arise □ When in a life-threatening situation

3. Who do you think should initiate Advance Care Planning (ACP) "most"?
   □ The patient themselves □ Nephrologist □ Palliative care physician □ Other specialist physician□ Dialysis nurse □ Palliative care nurse □ Close family member □ Other_____
4. Whom would you like to designate as your appointed agent? (Multiple choices allowed)
   □ Spouse □ Children □ Siblings □ Friends □ Lawyer □ Other_____
5. How much are you willing to pay out of pocket to participate in Advance Care Planning (ACP) consultation? (One-time) (US dollars)
   □ $33 □ $66 □ $99 □ $133 □ $167 □ $197 □ $263 □ $333
6. Who do you think should bear the cost of "Advance Care Planning consultation fees"?

□ Myself, fully □ National Health Insurance, fully □ Government, fully □ Charitable Foundation, fully □ Split between myself and relevant organizations

Table 6. Complete Questionnaire (in original languate, Chinese)

血液透析患者對預立醫療照護諮商與病人自主權利法之知識、態度與意願問卷

親愛的腎友您好：

我們是臺中榮總腎臟科與中臺科大醫管系研究團隊，目前正在進行「末期腎病患者對預立醫療照護諮商與病人自主權利法之知識、態度與意願」之研究，您的寶貴意見將有助於瞭解末期腎病患者及家屬對預立醫療照護諮商與病人自主權利法的意向，可供未來預立醫療照護諮商與病人自主權利法相關之參考。**（填答問卷前，請詳細閱讀名詞解釋）**

本問卷採不記名方式填答，收集一切的相關資料僅供學術研究分析使用，絕不對外公開，加以保密，敬請安心填答。謝謝您!

臺中榮總腎臟科　陳呈旭　主任
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名詞解釋

- **維持生命治療**：指心肺復甦術、機械式維生系統、血液製品、為特定疾病而設之專門治療、重度感染時所給予之抗生素等任何有可能延長病人生命之必要醫療措施。
- **人工營養及流體餵養**：指透過導管或其他侵入性措施餵養食物與水分。
- **預立醫療照護諮商(ACP)**：指病人與醫療服務提供者、親屬或其他相關人士所進行之溝通過程，商討當病人處於特定臨床條件、意識昏迷或無法清楚表達意願時，對病人應提供之適當照護方式以及病人得接受或拒絕之維持生命治療與人工營養及流體餵養。
- **預立醫療決定(AD)**：指事先立下之書面意思表示，指明處於特定臨床條件時，希望接受或拒絕之維持生命治療、人工營養及流體餵養或其他與醫療照護、善終等相關意願之決定。
- **醫療委任代理人**：指接受意願人書面委任，於意願人意識昏迷或無法清楚表達意願時，代理意願人表達意願之人。
- **特定臨床條件：**指符合下列臨床條件之一：一、末期病人。二、處於不可逆轉之昏迷狀況。三、永久植物人狀態。四、極重度失智。五、其他經中央主管機關公告之病人疾病狀況或痛苦難以忍受、疾病無法治癒且依當時醫療水準無其他合適解決方法之情形。
- **生命末期**：當各種方法的醫療均已無法治癒或控制疾病的進展時。

一、背景資料

1. 性　別：

□男　□女

2. 年　齡：

民國_____年生

3. 教育程度：

□國中以下 □國中 □高中職 □專科 □大學 □研究所以上

4. 婚　姻：

□已婚 □未婚 □離婚、分居 □喪偶 □其他

5. 宗教信仰：

□無宗教者 □民間信仰 □佛教 □道教 □天主教 □基督教

□其他

6. 居住狀況：

□獨居 □與家人同住 □與他人同住

7. 生活經濟狀況：

□工作收入足以支應 □積蓄或退休金足以支應 □依靠家屬親友支應

□依靠社會救助支應

8. 您目前是否有其他重要疾病？（可複選）

□高血壓 □心血管疾病 □糖尿病 □心臟衰竭 □缺血性心臟病 □血脂異常

□消化性潰瘍 □腦中風 □心律不整 □慢性阻塞性肺疾病 □癌症 □其他_____

9. 您目前使用的透析方式：

□腹膜透析（□APD □CAPD □APD+ CAPD）

□血液透析（每周□2 次 □3 次）

□腹膜透析與血液透析混合

10.接受透析治療時間：自民國_____年開始

11.您選擇現在透析方式的主要原因？

□醫師的指示 □自己的意願 □家人的期望

12.您是否（曾）從事醫療相關工作？

□是 □否

13.您是否對目前的透析決定感到疑惑？

□是 □否

14.您是否已簽署過不施行心肺復甦術(DNR)意願書或預立安寧緩和醫療暨維生醫療抉擇意願書？

□是 □否

15.是否有醫護人員與您及您的家人討論過透析的預後及預計存活時間：

□是 □否

16.是否有醫護人員與您或您的家人討論過病情惡化至危及生命時的醫療抉擇：

□是 □否

17.是否有醫護人員提供您或您的家人有關預立醫療照護諮商(ACP) 和預立醫療決定(AD)的資訊：

□是 □否

18.您是否曾經與您的家人討論過病情惡化至危及生命時的醫療抉擇：

□是 □否

二、預立醫療照護諮商(ACP)與病人自主權利法之**知識**

請就下列對於「**預立醫療照護諮商(ACP)與病人自主權利法之知識**」的題項，請依您對問項描述的**瞭解程度**選擇適合的選項（請您在覺得適合的□內打✓）	是	否
1. 在今天之前，您是否聽過預立醫療照護諮商(ACP)。	□	□
2. 在今天之前，您是否聽過預立醫療決定(AD)。	□	□
3. 在今天之前,您是否知道可以指定醫療委任代理人在您意識昏迷或無法清楚表達意願時，代理您表達表達醫療意願。	□	□
4. 您是否知道：台灣在民國 108 (2019)年開始實施病人自主權利法。	□	□
5. 您是否知道:在病人自主權利法中，病人可以簽署預立醫療決定(AD)，事先決定在生命末期時希望接受或拒絕的治療方式。	□	□
6. 您是否知道:在病人自主權利法中，醫護人員在病人無法自己做主時可以根據病人的預立醫療決定進行病人想要的治療方式。	□	□
7. 您是否知道:在病人自主權利法中，病人可以指定醫療委任代理人,在病人無法自己做主時為病人決定治療方式。	□	□
8. 您是否知道：即使簽署了預立醫療決定(AD)後，自己仍然可以改變原先的決定。	□	□
9. 您是否知道：醫療委任代理人可以不只一位。	□	□
請就下列對於「**預立醫療照護諮商(ACP)與病人自主權利法之知識**」的題項，請依您對問項描述的**瞭解程度**選擇適合的選項（請您在覺得適合的□內打✓）	是	否
10.您是否知道：簽署預立醫療決定(AD)後，需註記在健保 IC 卡上才能生效。	□	□

11.預立醫療照護諮商(ACP)與病人自主權利法之**態度**

請就下列對於「**預立醫療照護諮商(ACP)與病人自主權利法之態度**」的題項，請依您對問項描述的**同意程度**選擇適合的選項（請您在覺得適合的□內打✓）	非常同意	同意	沒意見	不同意	非常不同意
1. 預立醫療照護諮商(ACP)可以幫助您瞭解生命末期時各種可用的照護選擇以及其效益與風險。	□	□	□	□	□
2. 預立醫療照護諮商(ACP)可以增加家人與醫療團隊瞭解您在生命末期照護上的價值觀與意願，進而建立共識。	□	□	□	□	□
3. 預立醫療照護諮商(ACP)可以減少生命末期無效醫療的可能性。	□	□	□	□	□
4. 預立醫療照護諮商(ACP)讓您更有信心面對疾病最壞的結果，包括死亡。	□	□	□	□	□
5. 預立醫療照護諮商(ACP)能夠確保您在生命末期時的生活品質。	□	□	□	□	□
6. 預立醫療照護諮商(ACP)可以降低家人在為您進行醫療決策的心理負擔。	□	□	□	□	□
7. 預立醫療照護諮商(ACP)應可以定期進行討論，讓您檢視各種相關醫療處置的進展以及您的意願是否要改變。	□	□	□	□	□
8. 當您知道末期腎病（尿毒症）比其他疾病的死亡風險較高時，您認為參與預立醫療照護諮商(ACP)是有必要的。	□	□	□	□	□
9. 您認為末期腎病（尿毒症）病人，在進入透析的初期就應該開始進行預立醫療照護諮商(ACP)的討論。	□	□	□	□	□
10.預立醫療決定(AD)是當您在失去決策能力時，依然能為自己的醫療決策做主。	□	□	□	□	□
11.推行預立醫療決定(AD)可以減少在生命末期時承受不必要之痛苦。	□	□	□	□	□
12.預立醫療決定(AD)是依照您的價值觀和人生目標決定您的生命末期照護決策，可以有助於您獲得善終。	□	□	□	□	□

請就下列對於「**預立醫療照護諮商(ACP)與病人自主權利法之態度**」的題項，請依您對問項描述的**同意程度**選擇適合的選項（請您在覺得適合的□內打✓）	非常同意	同意	沒意見	不同意	非常不同意
13.您相信醫療委任代理人會在您意識昏迷或無法清楚表達意願時，依照您的意願代理您表達醫療決定。	□	□	□	□	□
14.您還沒準備好要進行預立醫療照護諮商(ACP)的討論。	□	□	□	□	□
15.討論預立醫療照護諮商(ACP) 難免會討論到死亡，這會讓您對人生感到沒有希望。	□	□	□	□	□
16.您認為醫師或護理人員沒有足夠的教育訓練能和您及您的家人討論預立醫療照護諮商(ACP)。	□	□	□	□	□
17.您認為醫師或護理人員沒有足夠時間和您及您的家人討論預立醫療照護諮商(ACP)。	□	□	□	□	□
18.簽署預立醫療決定(AD)的過程中必須思考死亡或失能，會讓人感到不愉快。	□	□	□	□	□
19.簽署預立醫療決定(AD)需花費很多時間。	□	□	□	□	□
20.若簽署了預立醫療決定(AD)，您會擔心自己被放棄治療。	□	□	□	□	□
21.簽署預立醫療決定(AD)是沒有必要的，因為相信愛您的人會替您做出正確的決定。	□	□	□	□	□
22.您認為即使簽署了預立醫療決定(AD)，您也無法確定需要用到時，醫療團隊會依照您的意願執行。	□	□	□	□	□
23.您擔心簽署的預立醫療決定(AD)，無法涵蓋未來的所有醫療決策。	□	□	□	□	□
24.簽署預立醫療決定(AD)，您擔心會減少醫療團隊在您生命末期時的醫療處置。	□	□	□	□	□
25.您已簽署不施行心肺復甦術(DNR)意願書或預立安寧緩和醫療暨維生醫療抉擇意願書，所以不需要再簽署預立醫療決定(AD)。	□	□	□	□	□
26.對您來說，簽署醫療委任代理人是不必要的，因為您不想給家人帶來心理負擔。	□	□	□	□	□
27.您並不認為目前的透析會危及到您的生命，所以從沒考慮過有關死亡的議題。	□	□	□	□	□

請就下列對於「**預立醫療照護諮商(ACP)與病人自主權利法之態度**」的題項，請依您對問項描述的**同意程度**選擇適合的選項（請您在覺得適合的□內打✓）	非常同意	同意	沒意見	不同意	非常不同意
28.您認為對末期腎臟（尿毒症）病人來說，延長生命治療比放棄維持生命治療更為重要。	□	□	□	□	□
29.病人自主權利法僅容許病人行使其拒絕醫療權，只能算是自然死亡，並不是安樂死。	□	□	□	□	□
30.病人本人對於病情、醫療選項及各選項之可能成效與風險預後，有知情之權利，對於醫師提供之醫療選項有選擇權與決定權，其他人不得妨礙。	□	□	□	□	□
31.病人就診時，醫療團隊應以其所判斷之適當時機及方式，將病人之病情、治療方針、處置、用藥、預後情形及可能之不良反應等相關事項告知本人。病人沒有反對，才能告知家屬或其他相關人士。	□	□	□	□	□
32.在進行預立醫療照護諮商(ACP)時，病人本人、至少一位二親等內親屬以及醫療委任代理人均必須參加。	□	□	□	□	□
33.簽署預立醫療決定(AD)必須先經由醫療團隊進行預立醫療照護諮商(ACP)，經醫療機構核章、公證人公證或二人以上在場見證，並且註記於健保 IC 卡後才能生效。	□	□	□	□	□
34.即使簽署預立醫療決定，仍然可以隨時以書面撤回或變更。	□	□	□	□	□
35.如果病人最新的醫療決定是選擇接受維持生命治療或人工營養及流體餵養，醫師應即刻按照病人意願執行。	□	□	□	□	□
36.如果病人最新的醫療決定是選擇不接受維持生命治療或人工營養及流體餵養，醫師仍應按照原來的預立醫療決定執行，直到 IC 卡註記變更程序完成。	□	□	□	□	□
37.病人指定之醫療委任代理人，應年滿二十歲以上並具完全行為能力，而且必須以書面委任。	□	□	□	□	□

請就下列對於「**預立醫療照護諮商(ACP)與病人自主權利法之態度**」的題項，請依您對問項描述的**同意程度**選擇適合的選項（請您在覺得適合的□內打✓）	非常同意	同意	沒意見	不同意	非常不同意
38. 醫療委任代理人於病人意識昏迷或無法清楚表達意願時，代理病人表達醫療意願，其權限包括聽取醫療團隊的病情告知、簽具同意書以及依病人預立醫療決定內容表達病人的醫療意願。	□	□	□	□	□
39. 醫療委任代理人有二人以上者，均可單獨代理病人執行預立醫療決定，不須全部到齊。	□	□	□	□	□
40. 病人如果符合末期病人、處於不可逆轉之昏迷狀況、永久植物人狀態、極重度失智等臨床條件之一，且有預立醫療決定者，醫療團隊可依病人的預立醫療決定終止、撤除或不施行維持生命治療或人工營養及流體餵養之全部或一部分。	□	□	□	□	□
41. 醫療團隊根據其專業或意願，有權可以不執行病人的預立醫療決定。	□	□	□	□	□

四、預立醫療照護諮商(ACP)對末期腎臟（尿毒症）病人的**重要性**

請就下列對於「**預立醫療照護諮商(ACP)與病人自主權利法的重要性**」之題項，請依您對問項描述的**重要性**選擇適合的選項（請您在覺得適合的□內打✓）	非常重要	重要	普通	不重要	非常不重要
1. 加強病人和家屬對疾病的瞭解，包括預後、治療選擇（透析治療、保守治療和緩和照護服務），以及這些治療選擇的可能結果。	□	□	□	□	□
2. 引導病人確定照護目標，包括失去行為能力與生命末期的時候。	□	□	□	□	□
請就下列對於「**預立醫療照護諮商(ACP)與病人自主權利法的重要性**」之題項，請依您對問項描述的**重要性**選擇適合的選項（請您在覺得適合的□內打✓）	非常重要	重要	普通	不重要	非常不重要
3. 配合病人的目標制定照護計畫，並納入病人對失去行為能力、符合特定臨床條件與生命末期照護時的意願。	□	□	□	□	□

4. 確保醫護人員在醫療決策時能按照病人預立醫療決定(AD)的意願。	□	□	□	□	□
5. 幫助病人確保生命的品質與尊嚴，以維持心靈上的平靜。	□	□	□	□	□
6. 加強病人與親友討論有關病人未來照護意願的機會。	□	□	□	□	□
7. 協助減輕病人和親友在進行醫療決策時所承受的情感負擔。	□	□	□	□	□
8. 協助病人為未來的照護決策指定醫療委任代理人。	□	□	□	□	□
9. 協助醫療委任代理人瞭解他/她在病人未來醫療決策中的角色與作用。	□	□	□	□	□
10.促進對病人、醫療委任代理人和醫護人員對病人價值觀和意願達成共同瞭解。	□	□	□	□	□

五、預立醫療照護諮商(ACP) 與病人自主權利法之**意願**

請就下列對於**「預立醫療照護諮商(ACP)與病人自主權利法之意願」**的題項，請依您對問項描述的**意願**選擇適合的選項（請您在覺得適合的□內打✓）	非常願意	願意	沒願意	非常沒願意
1. 您是否願意參與預立醫療照護諮商(ACP)。	□	□	□	□
2. 您是否願意簽署「預立醫療決定」(AD)。	□	□	□	□
3. 您是否願意鼓勵家人也參與預立醫療照護諮商(ACP)。	□	□	□	□
4. 您是否願意鼓勵家人也簽署「預立醫療決定」(AD)。	□	□	□	□
5. 您是否願意簽署「不施行心肺復甦術(DNR)意願書或預立安寧緩和醫療暨維生醫療抉擇意願書」。	□	□	□	□
6. 您是否願意簽署「預立醫療委任代理人意願書」指定醫療委任代理人。	□	□	□	□
7. 您是否願意在生命末期與特定臨床條件時，在醫師的建議下減少或終止透析。	□	□	□	□
8. 如果有一天被診斷特定臨床條件時，您是否願意接受「鼻胃管」的灌食治療。	□	□	□	□
9. 如果有一天被診斷特定臨床條件時，您是否願意接受「氣管內管插管」的治療。	□	□	□	□
10.如果有一天被診斷特定臨床條件時，您是否願意接受「體外心臟按摩」（CPR）的急救措施。	□	□	□	□

請就下列對於「**預立醫療照護諮商(ACP)與病人自主權利法之意願**」的題項，請依您對問項描述的**意願**選擇適合的選項（請您在覺得適合的□內打✓）	非常願意	願意	沒願意	非常沒願意
11.如果有一天被診斷特定臨床條件時，您是否願意接受「急救藥物注射」的急救措施。	□	□	□	□
12.如果有一天被診斷特定臨床條件時，您是否會考慮停止或減少透析。	□	□	□	□

六、 預立醫療照護諮商(ACP) 與病人自主權利法之其他相關問題

1. 您**”最”**想與誰討論您生命末期的意願？（單選）

□誰都不想 □腎臟科醫師 □安寧緩和醫療醫師 □其他專科醫師

□透析護理師 □安寧護理師□配偶 □子女 □手足 □朋友

□其他_____

2. 您**”最”**希望在什麼時期進行預立醫療照護諮商(ACP)？（單選）

□在健康的時候 □在發現腎臟功能降低的時候 □在腎功能惡化到需透析的時候 □在其他嚴重併發症開始出現的時候 □在生命危急的時候

3. 您認為預立醫療照護諮商(ACP) ”最”應該由誰提出？

□病人本人 □腎臟科醫師 □安寧緩和醫療醫師 □其他專科醫師

□透析護理師 □安寧護理師 □親近的家人 □其他_____

4. 您想指定誰當任您的委任代理人？（可複選）

□配偶 □子女 □手足 □朋友 □律師 □其他_____

5. 您願意自費多少錢參與預立醫療照護諮商(ACP)（單次）?

□1000□2000□3000 □4000 □5000 □6000 □8000 □10000

6. 您認為「預立醫療照護諮商費用」應由誰來支付?

□自己全額支付 □全民健保全額支付 □政府全額補助 □公益基金會全額支付 □自己與其他有關單位各付一半

Table 7. Reliability Analysis of the Knowledge, Attitudes, and Willingness Scale on Advance Care Planning (ACP) and Patient Autonomy Act among Hemodialysis Patients.

	Number of questions	**Pre-rest(α)**	**Formal test(α)**
Knowledge (KR20)	10	0.916	0.956
Altitude			
Goal of ACP and AD	13	1.000	0.983
Barrier of ACP and AD	15	0.983	0.916
patient right to autonomy act	14	0.988	0911
Importance	10	0.916	0.985
Willingness			
Willingness to Agree	7	0.976	0.965
Willingness for Life Support Treatment	5	0.950	0.843

Formal test: n=129

Pre-test: n=33

Figure 1. Research Framework