

Patients' Perspective of the Access to and Quality of Care for Chronic Kidney Disease: Insights From the DISCOVER CKD Qualitative Study

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Background and Objectives

- Real-world data on the experience of patients with chronic kidney disease (CKD), particularly regarding clinical management, treatment patterns, and health-related quality of life (QoL), are limited.¹
- DISCOVER CKD (ClinicalTrials.gov, NCT04034992) is a multi-country, non-interventional cohort study that aimed to characterize the epidemiology of CKD, including practice patterns and clinical management, and to describe their association with clinical outcomes including disease progression and important clinical events across the patient journey.¹
- Here, we describe findings from a qualitative interview substudy of the DISCOVER CKD prospective cohort, evaluating the access to and quality of care for CKD as reported by patients.

Methods

- Patients were recruited to participate in one-to-one telephone interviews, exploring experiences with CKD, including disease journey, interactions with the healthcare system, and experiences with and attitudes towards treatments.
- A target of 100 patient interviews was planned across four countries (Japan, Spain, the UK, and the USA): ~20–25 participants per country.
- To reach concept/information saturation, a minimum of 12 patients was required for each CKD stage (stage 2–5 without dialysis, stage 5 with dialysis) and type 2 diabetes (with/without).
- Participants were asked about:
 - Their perception of barriers to accessing care for CKD.
 - Their perception of positive and negative attributes of CKD care.
- Interviews were conducted in the local language by trained interviewers.
- Transcribed interviews were translated into English for coding and analysis.
- Data were coded using qualitative research software (MAXQDA Plus 2022 v22.3.0).
- The study received research ethics board approval and all patients provided written informed consent.

Results

- 103 patient interviews were analysed
- Baseline demographics and characteristics of interview participants are shown in Table 1.
- The mean (SD) time since CKD diagnosis was 9.5 (6.1) years.

Table 1. Characteristics of Interview Participants (N=103)

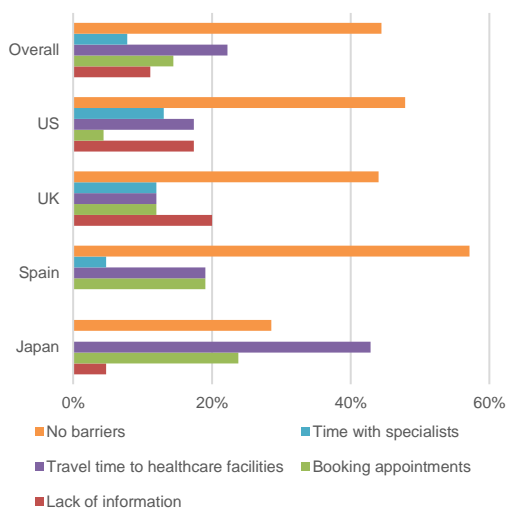
Characteristic	
Age, years, mean (SD)	63.1 (10.2)
Sex, female, n (%)	44 (42.7)
Ethnicity, n (%)	
White	70 (68.0)
Black/African American	5 (4.9)
Asian	24 (23.3)
Other	1 (1.0)
Not reported	3 (2.9)
Country, n (%)	
USA	29 (28.2)
UK	25 (24.3)
Spain	25 (24.3)
Japan	24 (23.3)
CKD stage, n (%)	
Stage 1	2 (1.9)
Stage 2	12 (11.7)
Stage 3A	23 (22.3)
Stage 3B	29 (28.2)
Stage 4	19 (18.4)
Stage 5 (without dialysis)	8 (7.8)
Stage 5 (dialysis)	10 (9.7)
Comorbidities, n (%)	
Hypertension	54 (52.4)
Type 2 diabetes	53 (51.5)
Cardiovascular disease	14 (13.6)
Heart failure	8 (7.8)

CKD, chronic kidney disease; SD, standard deviation.

Barriers to CKD care access

- Overall, regarding perceived barriers to care 44.44% (n=40/90) reported no barriers (Figure 1).
- Of the barriers reported, travel time to healthcare facilities was most frequently reported (n=20/90, 22.22%), followed by difficulties with booking appointments (n=13/90, 14.44%), lack of information (n=10/90, 11.11%) and available time with specialist (n=7/90, 7.78%).
- Country-level variations were observed with more Spanish participants reporting no barriers and travel time to healthcare facility considered most common barrier in Japanese participants.

Figure 1. Reported barriers to CKD care access

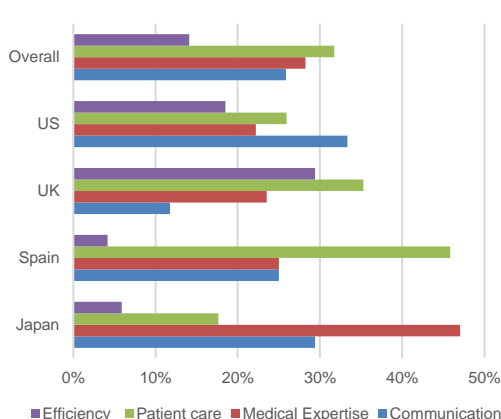


The number of patients per subgroup varies; concept/information saturation per subgroup was not assessed.

Positive attributes of CKD care

- Overall, 85 responses regarding positive attributes of CKD care were received that were further divided into 4 categories of communication, medical expertise, patient care, efficiency.
- Across all responses, patient care was mentioned most frequently (27/85, 32%), followed by medical expertise (24/85, 28.23%), communication (22/85, 25.88%) and efficiency (12/85, 14.11%).
- Country-level variations were observed with US participants reporting communication most often (9/27, 33.33%) while patient care was most frequently reported in the UK and Spain (6/17, 35.29% and 11/24, 45.83% respectively) (Figure 2).

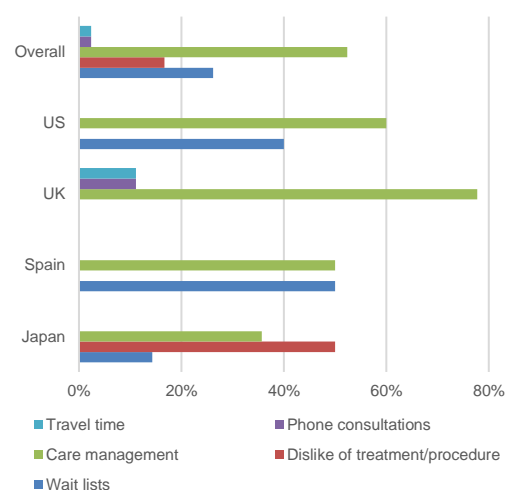
Figure 2. Positive attributes of CKD care



Negative attributes of CKD care

- Overall, 42 responses regarding negative attributes of CKD care were received that were further divided into 5 categories of waiting lists, dislike of treatment/procedure, care management, telephone consultations and travel time.
- Across all responses, care management was mentioned most frequently (22/42, 52.38%), followed by wait lists (11/42, 26.19%), dislike of treatment/procedure (7/42, 16.67%), phone consultations (1/42, 2.38%) and travel time (1/42, 2.38%) (Figure 3).
- Country-level variations were observed with the US participants reporting the fewest negative care aspects of wait lists (2/5, 40%) and care management (3/5, 60%) while the dislike of treatment/procedure was mentioned most frequently in Japan (7/14, 50%) (Figure 3).

Figure 3. Negative attributes of CKD care



Patient personal experience

Barriers to CKD care access

ID 1006, 65 years old, female, stage 3B

'The worst thing for me is **not knowing enough**. I've got to say that because I don't know, as I say, what is related to which. I don't know really that much about CKD other than, as I say, it's your filtration and you're not filtering things through properly. **Lack of information, I've got to say that. I hate not knowing things. I'd sooner know the worst scenario going than not, than knowing nothing.**

Positive attributes of CKD care

'The kindness and how they explain things to me, and all of that. How they tell me things and... Well, actually everything. They are very sincere. They explain things clearly and don't beat around the bush.'

ID 4025, 71 years old, male, stage 3B

Negative attributes of CKD care

ID 4006 53 years old, female, stage 4

'There are times when things are really busy, and the waits are a little bit long, but it's okay. I would change that. More nephrologists. More doctors in that specialty.'

Limitations

- Participant numbers in some subgroups were small; therefore, concept/information saturation may not have been achieved.

Conclusions

- In this multinational study, patients reported diverse barriers and negative attributes of CKD care. Measures to address these barriers could help optimise patient-centered care and improve outcomes.

References

1. Pecoits-Filho R et al. Clin Kidney J. 2021;14:1570–1578.

Disclosures

R.O.A., S.P., J.J.G.S., A.N. and E.P. are employees of, and may hold stock and/or stock options in, AstraZeneca.