

# **A Better Way to Measure Choices', Discrete Choice Experiment/Conjoint Analysis Studies in Nephrology - A Literature Review.**

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Published PDF deposited in [Curve](#) April 2016

**Original citation:**

Clark, M. D. , Higgins, R. , Gumber, A. , Moro, D. , Leech, D. , Szczepura, A. , Daga, S. and West, N. (2013) A Better Way to Measure Choices', Discrete Choice Experiment/Conjoint Analysis Studies in Nephrology - A Literature Review.. EMJ Nephrology 2013, volume 1 : 52-59

URL: <http://emjreviews.com/journals/nephrology-2013/>

Publisher: Gorely New Media

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# 'A BETTER WAY TO MEASURE CHOICES' DISCRETE CHOICE EXPERIMENT AND CONJOINT ANALYSIS STUDIES IN NEPHROLOGY: A LITERATURE REVIEW

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**Disclosure:** No potential conflict of interest.

**Citation:** EMJ Neph. 2013;1:52-59.

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## ABSTRACT

Discrete choice experiments (DCE) and conjoint analysis (CA) are increasingly used to address health policy issues. This is because the DCE and CA approaches have theoretical foundations in the characteristics theory of demand, which assumes goods, services, or healthcare provision, can be valued in terms of their characteristics (or attributes). As a result, such analysis is grounded in economic theory, lending theoretical validity to this approach.

With DCEs, respondents are also assumed to act in a utility-maximising manner and make choices contingent upon the levels of attributes in DCE scenarios. Therefore, choice data can be analysed using econometric methods compatible with random utility theory (RUT) or random regret minimisation (RRM) theory. This means they have additional foundations in economic theory. In contrast, analyses described as CAs are sometimes compatible with RUT or RRM, but by definition they do not have to be.

In this paper we review the CA/DCE evidence relating to nephrology. The CA/DCE approach is then compared with other approaches used to provide either quality of life information or preference information relating to nephrology. We conclude by providing an assessment of the value of undertaking CA or DCE analysis in nephrology, comparing the application of CA/DCEs in nephrology with other methodological approaches.

**Keywords:** Renal, nephrology, conjoint analysis, discrete choice experiments, literature review, transplantation, dialysis.

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## BACKGROUND

Table 1 provides an example of attributes and levels for conjoint analysis/discrete choice experiments (CA/DCE),<sup>1,2</sup> whilst figure 1 is a DCE question used for it. DCE and CA methods involve the characteristics theory of demand.<sup>3</sup> By definition, DCEs must conform to either random utility theory (RUT) or random regret minimisation (RRM).<sup>4,5</sup> However, sometimes CAs do not conform to RUT/RRM, so such analysis may not be rigorously grounded in economic

theory. This is because although CAs do conform to Lancaster's characteristic's theory of demand, they may not conform to RUT or RRM theory, whereas DCEs do.

If attributes are significant, data analysis confers information relating to how average the respondent's utility, or willingness to pay (WTP), is affected by changes in the levels of attributes, and the impact of different attribute levels upon choice can then be quantified. This information can help decide which

patient groups ought to be prioritised for kidney transplants, when dialysis should be provided, or which modality is used.

## METHODS - LITERATURE SEARCH

We conducted PubMed literature searches using keywords 'discrete choice experiment' or 'conjoint analysis' and 'renal transplant' or 'renal dialysis', reviewing DCE/CA papers identified. We also included a DCE conference abstract.<sup>6</sup>

## RESULTS

The literature searches revealed four papers, for three studies involving DCE/CA for renal transplantation.<sup>1,2,7,8</sup> Other DCE/CA studies (five papers, for four studies) relate to dialysis.<sup>9-12</sup> Preliminary findings (conference abstract) about a dialysis DCE,<sup>6</sup> are also considered. A summary of some key features of these studies is provided in Table 2.

### Renal Transplant DCE/CA Analyses

A Canadian renal transplant DCE<sup>8</sup> of 150 healthcare professionals, 169 patients, and 32 caregivers involved decisions about end-of-life care in chronic kidney disease. The DCE had six attributes, two related to transplantation: 'how should live kidneys for transplantation be obtained?' (levels of first come first served, or best match); and 'how should live kidneys for transplantation be obtained? (levels of family member, paired kidney exchange, anonymous donor, or buy a kidney). Other attributes included 'who provides comprehensive day-to-day care; when should end-of-life care discussions be started; how much information on prognosis end-of-life care issues should be provided, and how should decisions to stop dialysis be made?'. Findings suggested patients/healthcare professionals preferred detailed prognostic information, and shared to individual care planning, and co-ordinated care. For transplants they preferred 'best match' to 'first-come first served' allocation criteria, whilst donor donation by family members/friends was most preferred followed by an unknown donor, paired kidney exchange, and buying a kidney.

A USA study<sup>7</sup> involved a CA of 175 patients. It looked at preferences for accepting a kidney from donors at increased risk of blood-borne viral infection (DIRVI). It considered the influence of HIV infection risk, donor age, and transplant waiting time (years). Key findings were that 24% of respondents would not accept a DIRVI kidney at all, 58.9% would under some circumstances, and 17.7% always accepted DIRVI

kidneys. Patients would be more likely to accept a DIRVI kidney when waiting times were longer, donors were younger, and when HIV infection risk was lower. Dialysed patients and older patients were more likely to accept a DIRVI kidney. This is a CA, not a DCE, and so results may not be compatible with RUT/RRM, and may not be as rigorously grounded in microeconomic theory.

A UK renal transplant DCE study,<sup>1,2</sup> assessed preferences of 908 patients, 113 healthcare professionals, 48 live donors/relatives of deceased donors, and 41 carers. Attributes and levels are shown in Table 1.

Patients highly valued transplant waiting time and quality of tissue match, prioritising those with child or adult dependents and transplanting younger adults. Those with moderate diseases affecting life expectancy were prioritised over those with severe diseases, but those with moderate diseases affecting length of life were not prioritised over those without other disease(s). Patients prioritised those with moderate rather than no disease, and moderate rather than severe disease affecting quality of life. Ethnic minority patients did not prioritise recipients with close donor-recipient tissue matches, as this disadvantages them.

Healthcare professionals valued allocation based on tissue match less than patients, but valued prioritising those with dependents more. They also valued prioritising those with no diseases rather than moderate diseases affecting life expectancy, whereas patients did not. Healthcare professionals also valued prioritising those with severe rather than moderate diseases affecting quality of life more than patients. Carers did not value prioritising those with better tissue matches or those with dependents. However, they valued prioritising those with moderate, not severe, diseases affecting life expectancy more than patients. The live donors/relatives of deceased donors group did not value prioritising kidney transplants on the basis of tissue match. However, they valued transplants to those with dependents, younger recipients, and to those with moderate rather than severe diseases affecting life expectancy, more than patients.

Results are broadly in line with current UK renal transplant policy, but another criterion (whether recipients had adult or child dependents) was also valued, and differences in ethnic minority patient preferences were highlighted.

Attribute	Description of attribute in questionnaire preamble	Levels for the attribute that appear at different levels across questionnaire questions
A) Amount of time a person has waited for a kidney transplant	Timescales for people receiving a transplant after being placed on a waiting list are likely to differ. The waiting time could be (see next column)	1) 1 month. 2) 2 years. 3) 10 years.
B) Tissue type matching - and likelihood of transplant success	This affects the likelihood of a transplant proving to be successful. Below are the up-to-date figures from UK Transplant for the survival of all transplants in the UK. There are 6 main tissue types used in matching. A perfect tissue type match is all 6 types matching; favourable is 4-5 out of 6 matching, non-favourable is less than 4 matching. If a transplant fails the patient will return to renal dialysis (see next column)	1) Non-favourable tissue match (86% average survival rate of the kidney 1 year after the transplant). 2) Favourable tissue match (89% average survival rate of the kidney 1 year after the transplant). 3) Perfect tissue type match (90% average survival rate of the kidney 1 year after the transplant).
C) How many dependents (either children or adults) recipients have	Some respondents might consider that those who have <u>dependent</u> children, or others who are dependent either because of their age or a physical or mental handicap, ought to be prioritised for kidney transplant. So we assume that respondents might have (see next column)	1) No dependents. 2) 1 dependent. 3) 4 dependents.
D) Recipient age	The recipient could be aged either (see next column)	1) 20 years. 2) 45 years. 3) 65 years.
E) Diseases affecting life expectancy	As well as having kidney failure, someone may have other conditions prior to kidney transplantation which affect their life expectancy. Some of the conditions which reduce life expectancy may occur in young people, and some older people may be entirely healthy apart from kidney disease. We assume these could be either (see next column)	1) None. 2) Moderate diseases (uncontrolled hypertension or obesity). 3) Severe diseases (heart attack, stroke, or diabetes with complications).
F) Other recipient illnesses	Someone with kidney failure may have conditions other than kidney failure, which are not life-threatening but do affect their quality of life. Respondents might or might not wish to allocate kidneys according to such conditions. Examples would be (see next column)	1) Healthy except for kidney disease. 2) Kidney disease with a condition that sometimes affects their activities, such as mild asthma. 3) Kidney disease with a condition that affects their activities on a daily basis, such as severe arthritis.

**Table 1. Details of attributes and levels used in the UK renal transplant discrete choice experiments (DCE) preference study.**

NOW PLEASE READ DESCRIPTIONS OF OPTION A AND B AND INDICATE WHO YOU THINK SHOULD BE PRIORITISED FOR A KIDNEY TRANSPLANT – PATIENT A OR PATIENT B?:

	Patient A	Patient B
Amount of time a person has waited for a transplant	1 month	2 years
Tissue type match – and likelihood of transplant success	90% average 1 year chance of transplant success	86% average 1 year chance of transplant success
How many dependents (children or adults) recipients have	4 dependents	No dependents
Recipient age	20 years	45 years
Diseases affecting life expectancy	Moderate: Uncontrolled hypertension or obesity	Severe: Heart attack, or stroke, or diabetes with complications.
Other recipient illnesses (other than kidney disease)	Mild asthma	Severe arthritis

Which patient would you choose?  
(tick 1 box only)

Patient A  Patient B

**Figure 1. Details of the instruction appearing over questions, followed by the first discrete choice experiments (DCE) question used in the UK renal transplant DCE preference.**

### Dialysis DCE/CA Analyses

The aforementioned Canadian DCE,<sup>8</sup> included the attribute ‘how should decisions to stop dialysis be made?’ Findings revealed a preference for joint, over personal, decision-making for healthcare providers, patients, and caregivers.

A USA analysis<sup>10</sup> of 126 patients looked at switches from conventional dialysis (three times a week) to daily haemodialysis (six treatments of 2-3 hours weekly) to improve dialysis outcomes. This study included four attributes: life expectancy (levels of 6, 8 or 10 years), quality of life on a 1 to 10 scale (levels of 5, 7 and 9), annual number of hospitalisations (levels of 3, 2, and 1), and transport time (levels of transportation time which were 3, 2, or 1 times the reference case [i.e. travel time for conventional haemodialysis]). People were more willing to switch to daily dialysis when the regimen offered increased life expectancy and better quality of life, and when there were larger decreases in hospitalisations and transport time.

Another DCE<sup>9</sup> about nephrology facilities in Greenland (Denmark), estimated willingness-to-pay (WTP) for dialysis amongst 206 members of the general public. Its three attributes included numbers of specialists (levels of many specialists, one specialist, or monthly

visiting specialist), accommodation for patients (levels of patient hotel for Greenlandic people, patient hotel in Nuuk, or own apartment in Nuuk), and increased annual tax per person (levels of 0 DKK, 50 DKK, and 700 DKK). Findings suggested that alternatives involving treatment in Greenland were chosen in around two-thirds of cases, implying a tendency to favour treatment in Greenland even when it involves increased tax. Also WTP for patient hotel accommodation was higher than apartment accommodation, or having a permanent specialist. The authors concluded that Greenlanders’ perception of self-dependence and their attitude to health services in Denmark strongly impacted upon findings.

An Australian DCE study<sup>11,12</sup> involved well-conducted qualitative analysis to inform the attribute and levels selected.<sup>13-15</sup> One of the two DCE papers published by these authors surveyed 105 patients with stage 3-5 renal disease, evaluating whether patients preferred dialysis or conservative treatment. Attributes included differences in: life expectancy, weekly hospital visits, ability to travel, hours attached to a dialysis machine, treatment timing, availability of subsidised transport, and flexibility of dialysis schedules. Findings suggested patients were more likely to choose dialysis than conservative care if dialysis increased average life expectancy, if they

Study focus and authors	Country and type of study (DCE/CA)	Sample size	Type of attributes
End-of-life care in chronic kidney disease – kidney transplant. Davison et al. <sup>8</sup>	Canada, Renal transplant and dialysis (DCE)	169 Patients, 150 Healthcare professionals, 32 Caregivers	a) For whom should live kidneys for transplantation be provided? b) How should live kidneys for transplantation be obtained? c) Who provides comprehensive day to day care? d) How much information on end of life issues should be provided? e) How should decisions to stop dialysis be made?
Acceptability from donors at increased risk of blood-borne viral infection. Reese et al. <sup>7</sup>	USA, Renal Transplant (CA)	175 Patients	a) HIV infection risk b) Donor age c) Transplant waiting time (years)
Renal transplant prioritisation by stakeholders. Clark et al. <sup>12</sup>	UK, Renal Transplant (DCE)	908 Patients 113 Healthcare professionals 48 Live donors/ relatives of deceased donors 41 carers	a) Waiting period b) Tissue type matching c) Dependents d) Recipient age e) Diseases impacting life expectancy f) Other illnesses
Willingness to switch from conventional to daily haemodialysis. Halpern et al. <sup>10</sup>	USA, Dialysis (DCE)	126 Patients	a) Life expectancy b) Quality of life c) Number of hospitalisations d) Transport time
Willingness to pay for dialysis. Kjaer et al. <sup>9</sup>	Denmark, Dialysis (DCE)	206 People	a) Numbers of specialists b) Accommodation for patients c) Increase in annual tax per person
Dialysis modality preference of patients with CKD. Morton et al. <sup>11</sup> Factors influencing patient choice of dialysis versus conservative care. Morton et al. <sup>12</sup>	Australia, Dialysis (DCE)	105 Patients 73 Caregivers	a) Life expectancy b) Weekly hospital visits c) Ability to travel d) Hours attached to a dialysis machine e) Treatment timing f) Availability of subsidised transport g) Flexibility of dialysis schedule
Preferences for home-based haemodialysis or peritoneal dialysis or hospital-based haemodialysis. Higgins et al. <sup>6</sup>	UK, Dialysis (DCE)	663 Patients	a) Frequency of dialysis b) Quality of dialysis c) Type of care d) Timing of dialysis e) Dialysis costs to NHS

**Table 2. Salient features of discrete choice experiments/conjoint analysis renal transplant and dialysis studies included in review**



could dialyse during the day or evening not just the day, and if subsidised transport was available. Patients were less likely to choose dialysis if more visits to hospital were required, or with more restrictions on patient travel.

The other DCE published by these authors reports from the same study, but also reports results for 73 caregivers. Findings suggest home-based dialysis (either peritoneal or haemodialysis) was chosen by patients in 65% of cases, whilst the in-centre dialysis option was chosen in 35% of cases, and conservative care in 10% of cases. For caregivers, figures were 72%, 25%, or 3% respectively. Patients and caregivers preferred longer to shorter hours of dialysis, but were less likely to choose nocturnal than daytime dialysis. Patients would trade-off 23 months of life expectancy with home-based dialysis to decrease their travel restrictions, amongst caregivers the figure was 17 months.

The UK dialysis DCE<sup>6</sup> involved comparison of preferences for different modes of dialysis amongst 636 patients, comparing home-based peritoneal dialysis, unit-based haemodialysis, and home-based haemodialysis. Attribute levels, which included frequency of dialysis, quality of dialysis, level of care (self care, shared care, or professional care), timing of dialysis, and the costs to the NHS of dialysis varied across the labelled choices in line with feasible ranges for the modes of dialysis. Findings suggested that compared to dialysis unit haemodialysis, home peritoneal dialysis was valued positively, whilst home haemodialysis was valued negatively. Increasing dialysis frequency was negatively valued, but positively valued if it raised dialysis quality. More flexible dialysis timing was positively valued, whilst cost of dialysis provision to the NHS was statistically significant, but not highly valued.

## DISCUSSION

DCE/CA may be more rigorous than other methodologies. For example, if the alternative is a series of questions about how a respondent ranks options independently on a scale,<sup>16-18</sup> or involves preference ranking exercises<sup>19</sup> or choice scenarios.<sup>20,21</sup> This is because DCE/CA provide a robust method for measuring the preferences of stakeholders in dialysis and transplantation compatible with the characteristics theory of demand.

Other approaches to evaluation in nephrology involve assessment of health-related quality of life.<sup>22-28</sup> This may involve the use of validated quality of

life instruments.<sup>29</sup> However, such approaches have the disadvantage that they do not establish what patients prefer, which CA/DCE analysis does. Some analyses have tried to establish revealed preferences i.e. by looking at the characteristics of patients who do or do not switch dialysis therapy.<sup>30,31</sup> However, if such switches are driven by preferences, it is unclear whether they are renal physicians or patient preferences. In contrast, because DCEs can be used to compare the preferences of different stakeholder groups, differences in preferences between groups can be ascertained.<sup>1,2,8,11</sup>

Some other studies have tried to establish how respondents stated preferences for dialysis are related to patient characteristics,<sup>17,32</sup> and one study has looked at how nephrologist preferences for dialysis vary according to their characteristics.<sup>33</sup> Moreover, there are preference studies that do not involve DCE/CA methods, e.g. relating to establishing priority criteria for renal transplants.<sup>21,34,35</sup> However, a limitation of these types of studies is that they may fail to take into account the fact that preferences vary according to the characteristics of the different modes of dialysis, or may fail to robustly establish trade-offs between conflicting allocation criteria for kidney transplants because preferences are not related to attributes. In contrast, CA/DCE preference studies can establish how preferences are related to attributes of dialysis provision<sup>6,9,10</sup> or different priority criteria for transplants.<sup>1,2,8</sup>

Also, whilst there can be a useful role for using qualitative analysis to establish preferences,<sup>13,14</sup> there may be a very strong case for using such analysis to design DCEs<sup>11</sup> rather than to replace DCE analysis. When the authors of this paper have been involved in producing DCE questionnaires, both in relation to our transplant DCE,<sup>1,2</sup> and also our dialysis DCE,<sup>6</sup> we have been very keen to conduct rigorous qualitative analysis to determine the attributes and levels for the questionnaires before conducting the final DCE analysis. This adds enormous value over more traditional questionnaire approaches which may exclude this design step, and instead chooses attributes based upon researcher's preference. Moreover, if analyses are DCEs not CAs, the analysis will also be strongly grounded in RUT or RRM, as well as the characteristics theory of demand, so measured preferences should equate to respondents' actual preferences. One exception to this may be if an attempt is made to establish WTP.<sup>36</sup> A particular problem is that if WTP is calculated when healthcare provision is free at the point of use, choices posed

may lack realism. So valuations for the monetary attribute may be subject to hypothetical bias, biasing estimates of WTP. This is why, when we conducted our renal transplant DCE<sup>12</sup> we did not incorporate a monetary attribute. Moreover, for our dialysis DCE we did not present results in terms of WTP, instead valuing changes in other attributes versus increased dialysis frequency.<sup>6</sup> One analysis reviewed here<sup>9</sup> which calculated WTP may be biased because of a range of problems associated with calculating WTP using DCEs.<sup>36</sup> These include whether estimated WTP obtained via DCEs may be sensitive to factors including: the range specified for the monetary attribute, or the presence or absence of payment per se,<sup>37</sup> or the presence of a positive cost, rather than the level of cost indicated by the monetary attribute;<sup>38</sup> or the placement of the monetary attribute in the list of attributes.<sup>39</sup> Other evidence suggests that the way attributes are 'framed' may impact upon estimated WTP.<sup>40</sup>

## CONCLUSIONS

CAs and DCEs have the disadvantage of being more expensive to design, deliver and analyse than simple questionnaires, but extra expense may be justified if results are more meaningful/robust. Moreover, in renal transplantation, DCE results endorse factors such as waiting time and tissue type match as criteria for organ allocation, and raise important

questions about whether recipient co-morbidity and recipient social responsibilities should be included in organ allocation systems,<sup>1,2</sup> and about ethnic minority preferences. For dialysis, DCEs have yielded important information about when dialysis is indicated, and about preferences for different modes of dialysis.

It is difficult to provide an overview of all the potential additional applications of DCEs in nephrology, as DCEs could be used to address a wide range of additional nephrology research questions. However, if more studies are undertaken, in the interests of methodological rigour, they should be DCE analyses (not CA analyses which are incompatible with RUT/RRM). We would also point out that it is important to use rigorous qualitative analysis in the first instance in a pilot analysis, in order to establish what the attributes and levels specified in the DCE questionnaires are, before a DCE is conducted.

One possible future application of DCEs might be to establish healthcare professionals/patients' preferences relating to different characteristics for patient education in relation to dialysis provision. Also, there are other areas of self-management and therapy choices in nephrology, especially over non-dialysis care of the frail elderly, where being able to ask patients, professionals, and carers DCE-type questions would be useful.

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