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Patient Preferences for Early Diagnosis of Endometriosis and Associated Determinants in the United States: A Discrete Choice Experiment

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Abstract

Background: Endometriosis is a chronic and incurable gynecological disease that mainly affects women of reproductive age worldwide. It imposes clinical and economic burdens on patients, families, and society. A better understanding of the determinants of preferences towards early diagnosis of endometriosis may help develop programs and interventions to reduce the risk of more severe illness. We quantified patient preferences for early endometriosis diagnosis and explored whether preferences vary on the patient characteristics and pre-established social determinants of health.

Methods: A discrete choice experiment (DCE) was designed to elicit women's preferences and willingness to pay for early diagnosis of endometriosis. Women ages 18 and older were eligible to participate in the study. The attributes (and levels) considered to describe hypothetical scenarios included diagnosis (immediate/postponed), the chance of advanced endometriosis and more severe illness (low/high), time away from living, and professional activities (8 days, 15 days, 22 days and 30 days), and possible out-ofpocket costs ($0, $15, $60 and $210). The effects of participants' characteristics and social determinants of health on the preference for early diagnosis were modeled using a Tobit model.

Results: A total of 66 women with (2) or at-risk (64) of endometriosis completed the experiment. The respondents' age and insurance statuses significantly influenced their preference or choice for early diagnosis. On average, respondents were willing to give up $61.55 out-of-pocket cost to have a low risk of advanced endometriosis and more severe disease. The Tobit model indicates only age and insurance variables significantly affected early diagnosis preference. The results suggest that older ages and not having insurance increase the likelihood of respondents choosing early diagnosis than the younger age group and having insurance.

Conclusion: This study indicates the importance of considering the patient characteristics and social determinants of health when designing and implementing health programs and interventions for endometriosis.

Keywords: Willingness to Pay, Tobit Model, Attributes, Decision-Making, Optimal Design, Health Outcomes, Individuals' Characteristics, Age and Insurance Status

Background

Endometriosis is a disease that can affect all women of reproductive age, regardless of race, ethnicity, or socioeconomic status [1,2]. The literature defines endometriosis as the presence of the tissues of the endometrial lining outside the uterus inflaming areas of the body such as the ovaries, pelvis, abdominal cavity, and even the thorax and skin [2-5]. The disease imposes both clinical and economic burdens and concerns individuals and society. In addition to the clinical effects, endometriosis can profoundly impact women's quality of life. In fact, in a study that assessed the quality-adjusted life years, women described their experience of endometriosis to be worse than death [6,7].

There is no cure for endometriosis, and the treatment depends on several factors, including the disease's severity. Delays in treatment may exacerbate the burden of the disease and reduce the quality of treatment outcome [6,8,9,]. Delays in diagnosis, high hospital admission rates, surgical procedures, and incidences of comorbid conditions make endometriosis a more costly public health problem than other chronic conditions such as migraine and Crohn's disease [10].

Studies have shown that age and insurance access often influence decisions to seek early diagnosis and treatment for endometriosis [11, 12]. Younger adults and individuals without insurance are less likely to get a routine medical checkup and seek medical attention before a critical health issue [13]. A deeper understanding of the determinants of early diagnosis and treatments for endometriosis may help develop targeted programs and interventions to reduce the risk of more severe illness or reduce the impact of the disease outcomes [14,15]. In the absence of such critical evidence, women of reproductive age may continue to suffer clinical, humanistic, and economic burdens associated with endometriosis.

In this study, we quantified patient preferences for early diagnosis of endometriosis and explored whether preferences vary on the patient characteristics and pre-established social determinants of health.

No other DCE, to our knowledge, has addressed the role of age and insurance status in influencing preferences on early diagnosis of endometriosis. This study highlights the importance of accounting for individual preferences in improving decision-making for diagnosing and treating endometriosis.

Materials and Methods

DCEs have become a common technique in health economics research providing information on relevant characteristics (attributes) of services and programs [16]. Typically, a DCE elicits preferences that estimate individuals' value on a particular good or service [17, 18]. In this, the researcher asked respondents to choose between two or more alternatives among several scenarios in which they described several attributes regarding the good or service at different levels. One step in DCE is to gather demographics and socioeconomic information to help explain the individuals' preferences or choices. We collected several demographic information, including age and insurance.

Target population and subgroups

Women 18 years and older at risk for or diagnosed with endometriosis were eligible to participate in the study. Non-English-speaking individuals cognitively impaired needing a caregiver to complete a survey were excluded. We targeted women with potential risk for endometriosis and rich information on endometriosis. The literature defines women at risk for endometriosis as women currently menstruating, using replacement estrogen, and with opportunity for diagnosis [19]. This definition suggests a broad age group and characteristics and provided guidance in determining eligible participants for our research. This study identified suitable women aged 18-64 years. Still, it did not exclude older women if they have a history of endometriosis since they may add richness to the research. While endometriosis predominantly affects younger women, the most severe cases are found in older and postmenopausal women. Moreover, older women have a greater risk for endometriosis-associated ovarian cancer [20,21].

We excluded non-English speaking individuals from taking the survey since it was written only in English and otherwise invalid. In addition, a non-English language survey instrument would be costly, time-consuming, and difficult to validate. Because of the potential cognitive demands of the DCE instrument, we excluded individuals with cognitive impairment and who needed caregiver assistance in completing the survey from the survey.

Setting and location

We conducted the study in Tallahassee, Florida. We identified the eligible participants from various group settings, mainly among students, the general community setting, and a local community health center.

Sample size

Sample size calculations are complicated for DCE, and the literature has several recommendations for what it should be [22-25]. For this study, we based the sample size primarily on convenience.

Data collection

A pre-tested DCE survey instrument was hand-delivered to individuals at health clinics and other group settings to collect individuals' preferences effectively. The questionnaire gathered choice and demographic data such as age, race, education, insurance status, employment status, knowledge, endometriosis status (diagnosed or not), and annual household income. The second section of the questionnaire comprised the choice task with a series of 16 paired scenarios, each requiring respondents to select one of two options. The questionnaire included only the English language.

Discrete choice experiment

A discrete choice experiment instrument was created and administered to all participants (Table 1). The final attribute selection included diagnosis (immediate, postponed); chance of advanced endometriosis and more severe illness (low, high); time away from work, education, daily living activities (8 days, 15days, 22days, 30days), and cost to you not covered by insurance ($0, $15, $60, $210). We used literature search and expert opinion to define the attributes and levels and pre-test the survey with selected women willing to participate (n=10).

Attribute	Levels	Description
Diagnosis (Diag)	Immediate	Diagnosis of the disease is done now and not put off/ back. This choice may allow for early treatment.
	Postponed	Diagnosis of the disease is delayed or put off/back. This decision may lead to delayed treatment
Chance of advanced endometriosis and more severe illness (RISK)	Low	10% or less chance of advanced endometriosis and more severe illness
	High	Greater than 10% and up to 100% chance of advanced endometriosis and more severe illness
Time away from work, education, daily living activities (TIME)	8days	Average time for minimal cases of the disease
	15days	Average time for mild cases of the disease
	22days	Average time for moderate cases of the disease
	30days	Average time for severe cases of the disease
Cost to you (Not covered by insurance)[COST]	$0	Co-payment for preventive/wellness care
	$15	Co-payment for primary care visit for an illness
	$60	Co-payment for a specialist visit without surgery. This cost also includes imaging services
	$210	Average co-payment for surgery (ambulatory and outpatient hospital). Based on the average co- payment for three selected health insurance plans for ambulatory and outpatient surgery.

Table 1 Description of attributes and levels

Experimental design

We designed the DCE using the optimal design approach from the Street, Burgess, and Louviere [26] table format. This approach systematically coded the levels starting with 0 and counting according to attribute levels. For instance, "0, 1, 2, and 3" was coded for a 4-level attribute, and 0 and 1 for a 2-level attribute. The design permits one to choose a format that matches the number of levels and attributes in one's research plan. We used the Table 9 version optimal design for two 2-level and 4-level attributes (Table 2A&B). Table 2B comprises the level names of the different attributes of the study. The optimal design approach we used automatically checked for orthogonality, level balance, and minimal levels overlapping [26]. We asked respondents to choose their preferred treatment effect scenario from the options labeled A and B (Figure 1).

Set#	Option 1				Option 2			
	A1	A2	A3	A4	A1	A2	A3	A4
1	0	0	0	0	1	1	1	1
2	0	1	0	2	1	0	1	3
3	1	0	2	0	0	1	3	1
4	1	1	2	2	0	0	3	3
5	1	1	0	3	0	0	1	0
6	1	0	0	1	0	1	1	2
7	0	1	2	3	1	0	3	0
8	0	0	2	1	1	1	3	2
9	1	1	3	0	0	0	0	1
10	1	0	3	2	0	1	0	3
11	0	1	1	0	1	0	2	1
12	0	0	1	2	1	1	2	3
13	0	0	3	3	1	1	0	0
14	0	1	3	1	1	0	0	2
15	1	0	1	3	0	1	2	0
16	1	1	1	1	0	0	2	2

Table 2A Optimal design codes for two 2-level attributes and two 4-level attributes

Source: Street, Burgess, and Louviere, 2005, Table 9, p. 465

Set#	Option 1				Option 2			
	A1	A2	A3	A4	A1	A2	A3	A4
1	Post	Low	8days	$0	Immed	High	15days	$15
2	Post	High	8days	$60	Immed	Low	15days	$210
3	Immed	Low	22days	$0	Post	High	30days	$15
4	Immed	High	22days	$60	Post	Low	30days	$210
5	Immed	High	8days	$210	Post	Low	15days	$0
6	Immed	Low	8days	$15	Post	High	15days	$60
7	Post	High	22days	$210	Immed	Low	30days	$0
8	Post	Low	22days	$15	Immed	High	30days	$60
9	Immed	High	30days	$0	Post	Low	8days	$15
10	Immed	Low	30days	$60	Post	High	8days	$210
11	Post	High	15days	$0	Immed	Low	22days	$15
12	Post	Low	15days	$60	Immed	High	22days	$210
13	Post	Low	30days	$210	Immed	High	8days	$0
14	Post	High	30days	$15	Immed	Low	8days	$60
15	Immed	Low	15days	$210	Post	High	22days	$0
16	Immed	High	15days	$15	Post	Low	22days	$60

Based on: Street, Burgess and Louviere, 2005, Table 9, p. 465
Note: Post=Postponed; Immed=Immediate are the levels for the diagnosis attribute

Table 2B Optimal design for two 2-level attributes and two 4-level attributes

Attribute	Individual choice of interventions for endo treatment	
	Option A	Option B
Diagnosis	Immediate	Postponed (Delayed)
Chance of more serious/ severe illness	Low	High
Time away from work, education, and daily living activities	8 days	15 days
Cost to you (Not covered by insurance)	$15	$60
Which of the two options would you prefer? **(Check one)**	☐ Option (A)	☐ Option (B)

Figure 1. Example of our study choice set

Data collection

Women visiting at a local community health clinic, in the general public, and at students, gatherings were hand delivered the pre-tested survey instrument to complete independently. The cover letter of the questionnaire also served as informed consent. The letter informed participants that their participation was completely voluntary and of their right to withdraw at any time without penalty. Completed questionnaires were delivered directly to the research team/researcher for data inputting.

Data Analysis

The DCE experimental design and data analysis are directly linked. The response choice (Option A or Option B) is the dependent variable in the statistical model in which we estimated utility from observed choices. The data were organized and summarized with descriptive statistics (e.g., frequency, percentage and, standard deviation).

A mixed logit model with random effects was used to assess the impact of attribute levels on participants' preferences for early diagnosis of endometriosis. The variable cost was assumed log-normally distributed while the remaining variables were normally distributed. The model estimates the value or utility each respondent attaches to the different levels of the attributes and how the levels of the attributes impact individuals' choices. Using Hiligsmann et al. [27] as a guide, we specified the model in Equation 1.

$$Vij = \beta_0 + (\beta_1 + n_{1i})\,COSTj + (\beta_2 + n_{2i})\,TIME\_15dj + (\beta_3 + n_{3i})\,TIME\_22dj + (\beta_{41} + n_{4i})\,TIME\_30dj + (\beta_5 + n_{5i})\,IMMED1DIAGj + (\beta_6 + n_{6i})HIGH1RISKj + \varepsilon_{ij} \quad (1)$$

Where Vij indicates the utility that an individual i assigns to an intervention j. Vij is modeled as the sum of two parts: a systematic part based on the attributes in the DCE and an error or stochastic part (random component), E_{ij}. The random component is a function of the unobserved attributes and variation in an individual's preference [27,25]. β_0 is the constant reflecting the preferences for selected option or intervention relative to no option/intervention, (β_1 to β_6) the mean attribute utility weights in the population, and n_{1i} to n_{6i} error terms for individual-specific unexplained variation in the utility weights.

We coded the categorical variables (TIME, DIAG, and RISK) to reflect the levels of the primary attributes. For example, the variable labeled HIGH1RISKj refers to the attribute with the level of risk considered high. Out-of-pocket cost is the COST attribute treated as with the level of risk considered high. Out-of-pocket cost is the COST attribute treated as calculating the WTP values [25]. We used Dummy codes to describe the categorical variables (Table 3). At any given moment, one level will take a value of 1, and 0 for all others [25]. The coefficient signs reflect whether the attribute has a positive or negative effect on the intervention utility.

Attributes	Regression Label	Level	Modeling
Cost to you (out-of-pocket)	COST	$0	Continuous*
		$15	
		$60	
		$210	
Time away from work, education, and daily living activities	TIME	TIME_8d	Dummy variable
		TIME_15d	
		TIME_22d	
		TIME_30d	
Diagnosis	DIAG	IMMED1DIAG; POST2DIAG	Dummy variable
Chance of advanced endometriosis and more serious illness	RISK	LOW1RISK; HIGH2RISK	Dummy variable

Table 3. Attributes, regression coding, levels, and modeling

*Out-of-pocket cost is treated as a continuous variable in the regression model in the regression analysis, and it has given one column only (Unlike the categorical dummy attributes (WHO 2012, p.52)

We use the WTP to quantify an individual's tradeoff and utility by calculating the marginal substitution rate. WTP estimates for the categorical attributes were calculated as the ratio of the coefficients of the attributes (numerator) and cost attribute (denominator). A WTP value represents how much one is willing to pay (or give up) for a unit change in the attribute and is calculated by taking the ratio of the mean parameter for the attribute level to the mean parameter related to the cost (or other continuous quantitative variables). For example, what individuals are willing to pay, on average, to reduce the risk (chance) of advanced endometriosis and more serious (or for early [immediate] diagnosis). Likewise, they were willing to pay to spend less time away from work, education, and daily living activities. We use the mixed logit model (MXL) for the WTP estimates.

We used a Tobit model to investigate the effects of respondents' characteristics on their choice for immediate diagnosis. The Tobit model estimates a linear relationship between variables when either left – or right- censoring the dependent variable [28]. The dependent variable was the proportion of selected profiles that contained the attribute "immediate diagnosis" for each respondent. Because the Tobit model requires 15 observations per variable (participant-level characteristics) included in the model, a forward stepwise regression was conducted to identify statistically significant variables in predicting our dependent variable at a 5% significance level. We coded the respondents' background information (Section 3 of the survey), assigning a single identifier name for each question. For instance, questions 17 to 26 were named 'knowledge', 'information', 'diagnosed', 'stage', 'insurance', 'race', 'age', 'education', 'employment', and 'income' respectively. We used these as the independent variables in the analysis.

We tested the goodness of fit of the Tobit models using a log-likelihood ratio (LR) and Wald Chi-square tests. The data were analyzed using SAS version 9.4 and Stata version 12.0.

Assumptions

This study has several assumptions relating to the participants and the variables used. We assumed that the participants have the cognitive ability to make a rational choice independent of a caregiver and have some knowledge about endometriosis. This ability helped them make the tradeoffs in the decision-making process. We also assumed that the payment vehicle (cost attribute) represented the typical out-of-pocket healthcare cost for an individual seeking healthcare. We also took that the out-of-pocket cost means the actual co-payment insurance for preventive/wellness care, diagnostic and surgical procedures, and specialist visits. These assumptions imply that an individual has sought medical assistance (medical visit) at one time or the other.

We based the cost attribute on co-payments from selected HMO (Health Maintenance Organization) insurance providers such as Blue Cross/Blue Shield (Blue), Capital Health Plan (CHP), and Humana. We based cost attribute calculations on potential healthcare visits or care such as surgery (ambulatory and outpatient hospital), specialist, imaging, preventive care/ wellness, and primary care. These determined the four payment (cost attribute) levels. We averaged ambulatory and inpatient hospital copayment amounts for the three insurance plans to combine as one payment level ($210). Likewise, the specialist and imaging costs were combined to form another group ($60). Overall, the cost attribute included only network or referred provider cost based on a single visit for the specific care and the average of health plans co-payments per visit. Preventive care, also known as wellness care, costs is $0 for all health insurance plans. Co-payment for primary care visit for an illness is $15.

Results

We distributed 72 questionnaires to individuals, received 67 in return, representing a response rate of 93%. We excluded one questionnaire because the individual, per Hiligsmann and others' [27] recommendation, did not complete at least five of the choice sets in the DCE task. We included the remaining 66 (92%) questionnaires for data analysis. Respondents' socio-demographics and health characteristics are in Table 3. There was no restriction on participation based on individuals' race and ethnicity, but individuals were mainly black (about 72%). The other 28% comprises whites, Asians, Hispanics, and mixed races. Individuals were primarily in 19-29 and 30-49 age groups, and none of the respondents fell in the extreme upper (70+) or lower (18 or less) age groups. Of those responding, two (3.13%) were diagnosed with endometriosis but did not know the stage of their disease. The percent of those insured to some extent was 86.

We did a pre-test with 10 participants as face validity to test the entire survey instrument's clarity, ease (or difficulty), and comprehension. We gave the participants follow-up questions to determine their understanding of the DCE choice task and the length and ease of the instrument. Almost all participants indicated the choice task was straightforward, generally not tricky, and understandable. We also asked an endometriosis expert to evaluate the instrument's noteworthiness based on the contents. We revised and updated the survey instrument based on any comments or discourses.

		Frequency	Percent (%)
Age (years)			
	19 -29	34	52.31
	30-49	23	35.38
	50-69	8	12.32
	Missing	1	N/A
Educational Level (“Education”)			
	Grade school or less	2	3.08
	Some high school	1	1.54
	High school graduate	2	3.08
	Some college	14	21.54
	College graduate	24	36.92
	Graduate or professional degree	22	33.85
	Missing	1	N/A

Table 3. to be cont...

Employment Status (“Employment”)			
	Unemployed	6	9.23
	Employed part-time	16	24.62
	Employed Full-time	24	36.92
	Employed seasonally	0	0
	Retired	0	0
	Student	18	27.69
	Homemaker	1	1.54
	Missing	1	N/A
Annual Gross household income ("Income")			
	Less than $10,000	16	25
	$10,000 to $24,999	19	29.69
	$25,000 to $49,999	14	21.88
	$50,000 to $74,999	9	14.04
	$75,000 to $99,999	2	3.13
	$100,000 to $124,999	2	3.13
	$175,000 to $199,999	2	3.13
	Missing	2	N/A
Race/Ethnicity (“Race”)			
	Black/African American	46	71.88
	White/Caucasian	8	12.5
	Asian	2	3.13
	Hispanic	1	1.56
	Other (mixed races, Arab)	7	10.94
	Missing	2	N/A
Insurance coverage (“Insurance”)			
	Yes	56	86.15
	No	7	10.77
	Not sure	2	3.08
	Missing	1	N/A
Prior knowledge about endometriosis ("Knowledge")			
	Yes	51	78.46
	No	14	21.54
Where prior knowledge came from("Information")			
	School	20	30.77
	Work	4	6.15
	Healthcare practitioner	11	15.92
	Other	17	26.15
	No information	13	20
	Missing	1	N/A

Table 3. to be cont...

Diagnosed with endometriosis ("Diagnosed")			
	Yes	2	3.13
	No	62	96.88
	Missing	2	N/A
Stage at diagnosis ("Stage")			
	Not sure	2	3.08
	Not applicable	63	96.92
	Missing	1	N/A

Table 3 Summary of respondents' characteristics

Willingness to pay analysis

The WTP values for attributes levels are in Table 4. WTP results were not statistically significant, but the values are noteworthy economically. Though the results are not statistically significant, the values indicate that respondents would be willing to give up money 1) to put off their diagnosis for a later time, 2) to have an intervention that would lower their risk of endometriosis, and 3) to spend less time away from work, education and other daily living activities. For instance, respondents were willing (on average) to give up $61.55 out-of-pocket cost to have a low risk of advanced endometriosis and more severe disease.

Attributes and levels	**Willingness to pay (Conf. Interval)**
Diagnosis (Reference level: postponed)	-1.038 (-4.34, 2.86)
Chance of advanced endometriosis and more serious illness (reference level: Low)	-61.55 (-276.48, 153.38)
Time away from work, education, daily living activities (Reference level: 8days)	
TIME_15days	-15.27 (-68.69, 38.14)
TIME_22days	-8.19 (-36.51, 20.13)
TIME_30days	-16.58 (-74.42, 41.26)
CI: Confidence interval. Note: Data presented as mean (95% confidence interval overall), negative WTP means that individuals are willing to sacrifice out-of-pocket cost to receive the attributes/levels	

Table 4. Results of the willingness to pay analysis

Tobit model: Stepwise model selection results

The results of the stepwise Tobit model are in Table 4. The final model was statistically significant ($p < 0.01$) compared to an empty model. Of the variables introduced into the model, only age and insurance significantly affected early diagnosis preference.

Early/ Immediate diagnosis	**Estimated coefficient**	**Std. Error**	**t-value**	**P value**	**[95% Conf. Interval]**
Constant	0.41599	0.02755	15.1	0.000***	0.3609, 0.4711
Age	0.01995	0.00879	2.27	0.027**	0.0025, 0.0375
Insurance	0.02855	0.01351	2.11	0.039**	0.0015, 0.0556
Std. Error: Standard Error; Number of observations=62; 10 left-censored observations at early/immediate diagnosis <= 0.4375; 52 uncensored observations at early/ immediate diagnosis Log likelihood = 72.555689; Pseudo R2 =-0.0716 **p < 0.05; ***p < 0 .01					

Table 4 Stepwise Tobit model results

A. Tobit model: Effects of respondents' characteristics on preferences

Figure 2 shows the distribution of our dependent variable "proportion of selected profiles that contained the attribute immediate diagnosis" (prop_early). The data is left-censored, with our dependent variable being observable only between the values 0.4375 (lower bound) and 0.6875 (upper bound). The visual inspection of the data supports using a Tobit model to analyze the data. The results of the Tobit model are in Table 5. The overall model was statistically significant ($p < 0.05$).

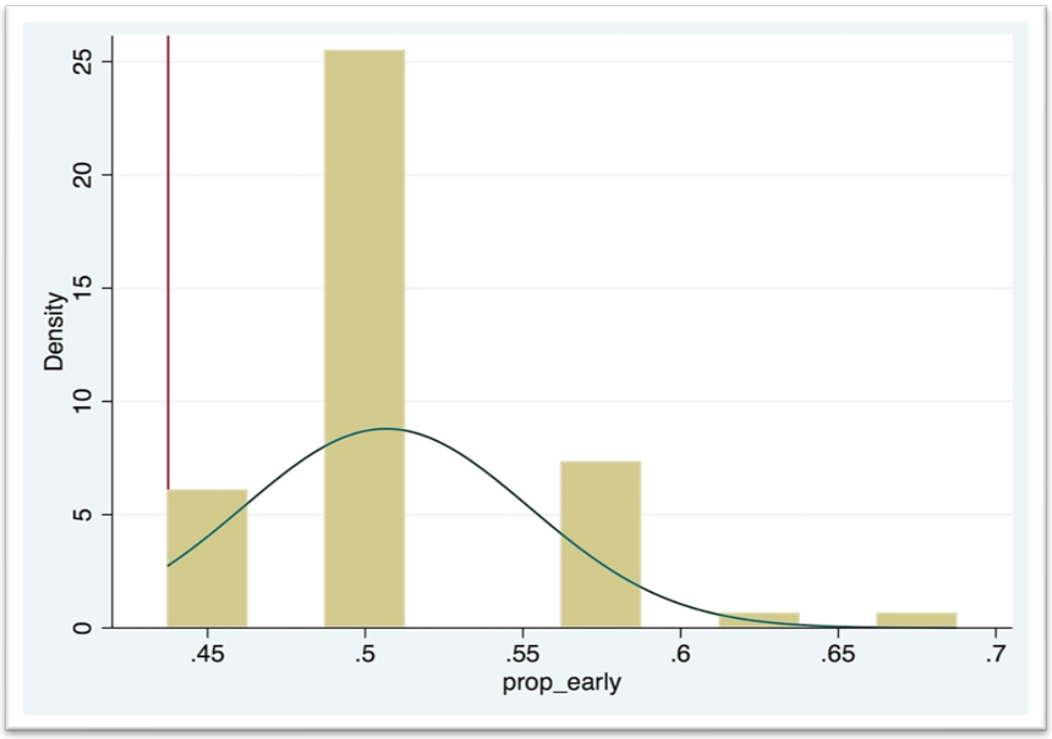

Figure 2. Distribution of the dependent variable prop_early

Note: prop_early: proportion of selected profiles that contained immediate diagnosis, per individual

Early/Immediate diagnosis	Estimated coefficient	Std. Error	t-value	P value	Conf. Interval
Constant	0.4842	0.0087	55.87	0.000***	0.4669, 0.5075
Age (Reference: 19-29 yrs)					
30-49 yrs	0.0253	0.0131	1.94	0.057*	-0.0008, 0.0515
50-69 yrs	0.0371	0.0191	1.94	0.057*	-0.0012, 0.0753
Insurance (Reference: Having insurance)					
No insurance	0.0399	0.0196	2.04	0.046**	0.00076, 0.0791
Not sure	0.03439	0.0344	1.00	0.322b	-0.0344 , 0.1032
Yrs: Years; Std. Error: Standard Error; Conf. Interval: Confidence interval; Number of observations=65 10 left-censored observations at early/immediate diagnosis <= 0.4375 55 uncensored observations at early/immediate diagnosis Log likelihood = 77.968594; Pseudo R2 =-0.0761 *p < 0.1; **p < 0.05; ***p < 0 .01; bNot significant					

Table 5. Tobit model: Effects of respondents' and insurance status on preference of early diagnosis

As mentioned before, we modeled only age and insurance to explain the effect of preference on early diagnosis. The estimated coefficients of the variables had positive signs, which suggest positive effects (increase) on the dependent variable prop_early. The results indicate that older age and not having insurance increased the likelihood of respondents choosing immediate or early diagnosis compared to the younger age group and having insurance, respectively. For example, if the dependent variable prop_early were not censored, the

estimated coefficient for age category 30-49 years (0.0253) would mean that prop_early is 0.025 points higher for respondents in 30-49 to respondents in the age group 19-29. Likewise, the estimated coefficient for no insurance (0.0399) would mean that prop_early is 0.04 points higher for respondents in the category of no insurance than respondents with insurance. Since the data are censored, then it is latent censored variable y that is linearly related with the independent variables age and insurance. As a result, a marginal effect analysis of the effect of the variable age and insurance is needed to draw more accurate conclusions.

B. Tobit model: Marginal effects of respondents' characteristics on preferences

The results for the Tobit marginal effect analysis are in Table 6. The marginal effects calculated the exact change on the truncated expected value of our dependent variable prop_early. For example, being aged 19-29 would cause the truncated expected value of prop_early to increase by 0.854 points.

Delta-method					
	Margin	**Std. Error**	**z-value**	**P value**	Conf. Interval
Age					
19-29 yrs	0.854	0.048	17.83	0.000	0.760, 0.948
30-49 yrs	0.942	0.030	31.09	0.000	0.883, 1.001
50-69 yrs	0.965	0.030	31.76	0.000	0.905, 1.0241
Insurance					
Have insurance	0.886	0.036	24.91	0.000	0.817, 0.956
No insurance	0.977	0.022	44.11	0.000	0.933, 1.020
Not sure	0.970	0.045	21.72	0.000	0.883, 1.058

Table 6. Tobit model: Marginal effects of respondents' age and insurance status on the preference of early diagnosis

Conf. Interval: Confidence interval; Std. error: Standard error; Number of observations=65; Censored (observable) expected value (y*) is (0.4375, 0.6875

Discussion

Study findings

This study, to our knowledge, is the first to use DCE to examine the role of age and insurance status in influencing preferences on early diagnosis of endometriosis. Our mixed logit model results suggest that respondents prefer to put off diagnosis later. Given that our participants are generally younger individuals (ages 19-29) may shed some light regarding why women do not get diagnosed early. Furthermore, our results indicate that individuals without insurance are more likely to prefer immediate/early diagnosis of endometriosis, which is not generally what we would expect. However, studies suggest that being insured does not guarantee an early diagnosis of a condition, and non-Hispanic blacks (compared to non-Hispanic whites) are less likely (even insured) to get an early diagnosis [29]. Our respondents were mainly non- Hispanic blacks, which might explain the differences.

A Tobit model was estimated to explain the impact of the respondents' characteristics on the choice for early diagnosis. This evaluation attempted to answer what factors prompt women toward earlier diagnosis and why they do not get diagnosed early. The significant explanatory variables were age and insurance. The results suggest that older individuals and those without insurance prefer early diagnosis. Studies showed that younger individuals delay seeking medical attention than their older counterparts.

Limitations

While the Tobit model seemed to be the best fit for our data, given a censored distribution of our dependent variable, there were limitations to its use. For example, the Tobit model generally requires at least 15 observations per variable included, while our data only contained 66 observations with several patient-level variables. Therefore, we had to remove some variables before modeling the data, impacting the results' accuracy. The mean WTP results were not statistically significant, but the values are noteworthy economically. The negative signs of the values reveal that individuals are willing to give up the out-of-pocket cost to avoid difficult or uncomfortable situations. At the same time, ordinarily, they would prefer low out-of-pocket costs. This concept is consistent with common sense logic and other DCE studies [30].

Generalizability and Current knowledge

This study could benefit health professionals and decision-makers, especially given the long delays diagnosed with endometriosis. This study provides opportunities to explore programs and products to improve treatment outcomes of endometriosis by considering individuals' preferences. For instance, the results indicate that younger individuals are more likely to postpone diagnosis, suggesting the need for programs targeting youths and younger adults, perhaps highlighting the long-term benefit of early diagnosis. In addition, the wide variation in the individuals' preferences highlights the importance of incorporating individuals' preferences and informed and shared decision-making processes in improving endometriosis treatment and outcomes.

Conclusion

No other DCE addressed the role of age and insurance status in influencing preferences on early diagnosis of endometriosis. This study highlights the importance of accounting for individual preferences and demography in improving decision-making for diagnosing and treating endometriosis. The respondents' age and insurance status significantly influence their choice for early diagnosis. The respondents' preferences' results provide opportunities to examine current practices. Since this was exploratory research, we recommend further investigation about the influence of age and insurance status on the decision for early diagnosis of endometriosis. Future studies may investigate more diverse demographics and spatial impacts.

Additional/Supplemental file

Additional file: data on the selection of attributes used in DCE?

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List of abbreviations

ACOG	American College of Obstetricians and Gynecologists
ASRM	American Society of Reproductive Medicine
CHP	Capital Health Plan
Diag	Diagnosis
DCE	Discrete choice experiment
HMO	Health Maintenance Organization
Immed	Immediate
Post	Postponed
Prop_early	Proportion of preferences on immediate diagnosis
SAS	Statistical Analysis Systems
Stata	Data analysis and statistics
WERF	World Endometriosis Research Foundation
WHO	World Health Organization
WTP	Willingness to pay

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