Preferences for fertility in women with pelvic inflammatory disease

Thomas J. Songer, Ph.D., a Judith R. Lave, Ph.D., b Mark S. Kamlet, Ph.D., c Shane Frederick, Ph.D., d and Roberta B. Ness, M.D., a for the Pelvic Inflammatory Disease Evaluation and Clinical Health (PEACH) Study

University of Pittsburgh and Carnegie-Mellon University, Pittsburgh, Pennsylvania

Objective: To identify the value that women with pelvic inflammatory disease (PID) assign to the health impact of future infertility.

Design: Cross-sectional observations on patient preferences.

Setting: Participants in an existing multicenter clinical trial of PID treatment options.

Patient(s): Five hundred thirty-two women with signs and symptoms of PID who were identified from emergency departments and sexually transmitted disease clinics.

Intervention(s): Women were asked to rate whether life with future infertility was more or less meaningful than life with each of seven chronic health conditions: sinus congestion, insomnia, chronic headache, asthma, incontinence, dialysis, and paralysis.

Main Outcome Measure(s): Preferences regarding future infertility.

Result(s): Most respondents rated future infertility as being worse than sinus congestion and asthma but better than the health impact of incontinence, dialysis, and paralysis. There was a wide range of opinion, with 18% viewing future infertility as minor (better than all conditions) and 5% viewing it as extremely important (worse than all conditions). Future infertility ratings were influenced by race, parity, difficulty in conceiving, and views on the importance of future pregnancy.

Conclusion(s): The majority of women with PID rate future infertility as a significant issue. Optimizing access to infertility treatment may affect the quality of life for such women. (Fertil Steril 2004;81:1344–50.

Key Words: Pelvic inflammatory disease, patient preferences, infertility, health services research

Pelvic inflammatory disease (PID) is a dynamic clinical condition representing upper genital tract infection. Long-term implications of PID include higher rates of infertility, ectopic pregnancy, and chronic pelvic pain (1–3). Fertility preservation is a major goal in developing optimal treatment strategies for PID.

About 10% of the population of childbearing age is affected by infertility (4, 5). Research on the impact of infertility on quality of life is very limited. Existing reports suggest that women who are infertile may be more likely to experience social isolation, depression, and impaired job performance (6–9). However, there is little published information available concerning how women in general value infertility and how they rate its potential importance in their lives. Existing information often originates from the clinics and centers that treat women with fertility difficulties (10, 11). The views of these women, though, may be quite different from those of women who do not seek services or from those of women who are at high risk for infertility, such as women with PID.

Recent evidence suggests that many affected women do not use fertility services (12), often because of factors such as limited availability of services, limited insurance coverage, or the high cost of treatment (13).

The objective of this paper is to assess the perceptions about infertility among women with PID. We report here on how these women rate a future life in which they are no longer able to become pregnant or have children, relative to one in which they suffer from one of seven other health states. We also report on the characteristics of women who rate future infer-
tibility as extremely aversive and those who view it as a minor issue.

MATERIALS AND METHODS

Study Participants

Women for this study were identified from among 831 participants in the Pelvic Inflammatory Disease Evaluation and Clinical Health Study, a randomized clinical trial of treatment options for women with the signs and symptoms of PID. The goal of the clinical trial was to evaluate the effectiveness of outpatient antibiotic treatment relative to inpatient antibiotic treatment. Pelvic inflammatory disease was defined in the clinical trial by the following criteria: [1] a history of pelvic discomfort for a period of ≤30 days, [2] findings of pelvic organ tenderness (uterine or adnexal) on bimanual examination, and [3] leukorrhea and/or mucopurulent cervicitis and/or untreated but documented gonococcal or chlamydial cervicitis.

Several characteristics disqualified women from participation in the clinical trial. These included an existing pregnancy; antibiotic use within the previous week; a history of hysterectomy or bilateral salpingectomy; an abortion, delivery, or gynecologic surgery in the previous 14 days; suspicion of a condition requiring surgery; allergies to study medication; and homelessness. All participants in the clinical trial were identified from emergency departments, clinics, and sexually transmitted disease units in seven primary and six secondary medical sites representing the eastern, southern, and central regions of the United States. Further details on the methods applied in the clinical trial are available elsewhere (14).

A survey identifying the preferences assigned to future infertility was collected from all participants in the clinical trial as one part of a follow-up interview that was conducted 1 year after randomization. The surveys were completed via a telephone interview or, in the few situations in which no phone contact could be established, by personal interview. Responses were received from 532 clinical trial participants through January 2000. These survey results form the basis of the study reported herein.

The University of Pittsburgh Institutional Review Board approved the methods and survey instruments that were used in the clinical trial. Informed consent was obtained from all study participants.

Study Measures

A quasi–rating scale preference measure using paired comparisons was developed to assess the value that participants assigned to future infertility. In this survey, each study participant rated the importance of future infertility by indicating her preferences in seven health state comparisons (infertility vs. sinus congestion, insomnia, chronic headache, asthma, incontinence, paralysis, and dialysis, respectively). Participants were given a brief description of infertility (“you would not be able to become pregnant or bear children”) and each chronic health state and were asked to identify which problem would be worse (e.g., asthma or infertility, incontinence or infertility). A copy of the survey instrument is available upon request.

The seven health conditions included in the survey were selected to satisfy two primary criteria. First, the conditions needed to reflect chronic rather than acute health conditions, because infertility represents a long-term concern to those affected. Second, the comparative health conditions had to represent a range of health states from less serious to more serious to allow a determination of how infertility was rated among conditions with varying influences on quality of life. Prior research on the quality of life and/or utility that was associated with each of the listed health conditions indicates an influence in the following order (from least to most severe impact): sinus congestion, insomnia, chronic headache, asthma, incontinence, paralysis, and dialysis (15–19). With this methodologic approach, it was possible to identify how participants rated the impact of future infertility relative to the quality of life for each health condition and to assess the relative severity that participants assigned to the infertility rating.

Several underlying factors could potentially affect the participants’ ratings. To consider possible influences on infertility ratings, additional information on age, race, education, marital status, pregnancy history, prior childbearing, and health status was obtained from the baseline surveys completed by the participants on entry into the clinical trial. Health status measures included a reported history of PID, history of sexually transmitted disease (defined as any occurrence of chlamydia, gonorrhea, syphilis, trichomonas, or bacterial vaginosis), verified HIV, and responses to the Short Form-36 health status instrument. Difficulty in achieving pregnancy was assessed at both the baseline survey and the 1-year follow-up interview in the clinical trial. Current difficulty in conceiving was defined by participant reports of ≥1 year of unprotected intercourse without pregnancy.

Information was also available from the clinical trial (baseline surveys) on the participants’ views regarding the importance of future pregnancy and the level of distress they would have if they were unable to get pregnant in the future. Both questions were assessed by using a 10-point Likert scale. Responses to each question were subsequently categorized into three groups to identify women placing strong emphasis on future pregnancy or the level of distress if they were unable to become pregnant (top 3 points on the Likert Scale), women placing weak emphasis (bottom 3 points on the scale), and women reflecting relative indifference (middle points on the scale).

Data Presentation and Statistical Analysis

Data analysis in the study focused on the descriptive evaluation of the responses to the health state preference
survey. We first determined how frequently women rated infertility as worse than each of the seven chronic health conditions. Chi-square and t test statistics were used to examine the influence of demographic, health, and pregnancy factors on each rating. For simplicity in presentation, the tables illustrate how infertility was rated relative to three of the chronic health conditions: sinus congestion, chronic headache, and paralysis. These three health states represent a spectrum of quality of life as reported in the literature—from least impact on quality of life (sinus congestion) to greatest impact on quality of life (paralysis).

Logistic regression analysis was conducted to assess the independent association of demographic and pregnancy factors on the infertility rating. In the models considered, the rating between infertility and sinus congestion, chronic headache, or paralysis was the dependent variable of interest. Women who viewed infertility as more serious than the comparison condition were assigned a value of 1; a value of 0 was assigned otherwise. Age, race, marital status, current difficulty in conceiving, number of live births, number of pregnancies, views on the current number of children, and views on the importance of future pregnancy were examined as independent variables. All analyses were performed by using the SPSS statistical software (20).

RESULTS

Characteristics of the Respondents

Table 1 presents information on the baseline demographic, health, and pregnancy characteristics reported by the participants. The study subjects were primarily young (under 24 years of age), unmarried, and African-American (78%). Most participants reported having a high school education or less, and 28% of the group reported a previous episode of medically treated PID. Nearly 40% of the group was nulliparous, and 20% self-reported infertility. However, of the 102 women self-reporting infertility at the time of clinical trial randomization, 10 women reported prior pregnancies, and 32 subsequently became pregnant in the 1-year follow-up period. Thus, infertility without pregnancy was noted in 11% of the cohort.

The perceptions reported by the participants concerning parity and future pregnancy are outlined in Table 2. Most participants reported having a high school education or less, and 28% of the group reported a previous episode of medically treated PID. Nearly 40% of the group was nulliparous, and 20% self-reported infertility. However, of the 102 women self-reporting infertility at the time of clinical trial randomization, 10 women reported prior pregnancies, and 32 subsequently became pregnant in the 1-year follow-up period. Thus, infertility without pregnancy was noted in 11% of the cohort.

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Patient Preferences Regarding Infertility

Figure 1 illustrates the average ranking for future infertility provided by the participants for each of the seven chronic health conditions.
health condition comparisons. Overall, 63% of the women regarded future infertility as worse than chronic sinus congestion, 48% rated infertility as worse than chronic headache, and 12% viewed infertility as worse than paralysis. Two conditions were generally seen as preferable to infertility: sinus congestion and asthma. Three conditions were consistently rated as worse than infertility: incontinence, dialysis and paralysis. Respondents were almost equally divided in their ratings of future infertility relative to insomnia and chronic headache.

There was considerable variation among the women with respect to their rating of future infertility. At the extremes, 18% of the women viewed all seven health states as being worse than future infertility. Five percent regarded future infertility as being worse than all of the health states, including dialysis and paralysis.

**Influences on Patient Preferences Regarding Infertility**

The opinion of the women regarding future infertility was systematically linked to several demographic, pregnancy and parity factors. Age and race were the strongest demographic factors influencing the ratings given on future infertility (Table 3). Younger women (<24 years of age) and non-blacks, independently rated future infertility differently and more severely than did older women and African-Americans. This was most evident when considering the ratings given to the comparisons between sinus congestion and infertility, and chronic headache and infertility. Nearly all of the women regarded paralysis as worse than infertility independent of age or race influences. Views regarding infertility did not differ significantly within any of the marital status, education, or health status measures (history of PID, history of STD, verified HIV, or Short Form-36 scores) assessed.

Pregnancy and parity factors also influenced the ratings regarding future infertility (Table 4). Women with no previous pregnancies or with no children rated future infertility as a more severe condition than did women with previous pregnancies or with children. A trend was observed with respect to parity, where future infertility was increasingly regarded as being worse than sinus congestion, chronic headache, or even paralysis as the number of children declined. Nearly 20% of the women who were nulliparous felt that future infertility was worse than paralysis. Women with a self-reported history of infertility generally rated the impact of future infertility as worse than both sinus congestion and chronic headache, but not paralysis. Also, participants who reported future pregnancy as being very important rated future infertility more severely than did women who believed that future pregnancy was less important (data not shown).

Multivariate analysis was conducted to determine the relative importance of the demographic and pregnancy factors examined. Overall, race (non-blacks), self-reported infertility, parity (those with no or fewer children), and the
importance of future pregnancy (very important) remained as significant variables explaining an elevated importance placed on future infertility in the health condition comparisons (data not shown). To consider the possible confounding influence of current infertility on the analysis, we also examined multivariate models in persons with and without self-reported, current infertility. For women reporting never having had periods of infertility, race, number of births, and the importance of future pregnancy were all significantly associated with the rating given to future infertility. However, among women who reported periods of infertility (n = 70), none of the demographic or pregnancy factors in the model remained significantly associated with the ratings given to future infertility. This finding suggests that the primary factor influencing the value assigned to future infertility was current infertility itself.

**DISCUSSION**

Infertility has long been recognized as an adverse outcome that is associated with PID. Little research, however, has examined the views of women with PID regarding infertility. An understanding of these perceptions may shed light on the desire for infertility services in this population and provide some, though not definitive, context to the complex issue of compliance with taking antibiotics in PID. The results indicate that future infertility is a significant concern for the majority of women with PID. The preference for fertility is rated particularly high by women with previous yearlong periods of unprotected intercourse without resultant pregnancy. Caucasians, women with no children, and women who strongly desired future pregnancy also rated future infertility as being particularly aversive to their quality of life.

Previous preference-based studies in the fertility domain have examined the factors affecting the decision for which type of fertility service to pursue (10, 21), assessed the preference for specific interventions in tubal pregnancy (22), or assessed the willingness to pay for IVF (11). These reports have focused almost exclusively on women who were attending fertility clinics or receiving fertility services, and the preferences reported may not reflect the perspective of all women regarding pregnancy. Unlike previous reports, our findings address the fundamental issue of the desire for fertility in a high-risk population not seeking infertility services. Notably, our study population and related results are skewed towards the perspective of low-income, minority women.

In the field of study of patient preferences for health conditions, most reports seek to assign a common utility or quality of life score to the health state examined. By this standard, future infertility was rated by the respondents in this study as being most close to the impact of insomnia or chronic headache. Both of these conditions represent the middle range in the quality of life spectrum examined (15–19). However, this statement of central tendency can obscure the variation in preferences that was reported across the women.

There was a wide range of opinion noted in the ratings provided by the women in this study. For example, 5% of the

**TABLE 3**

Participant preferences for future infertility by demographic characteristics.

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Sinus congestion</th>
<th>Chronic headache</th>
<th>Paralysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>63</td>
<td>48</td>
<td>12</td>
</tr>
<tr>
<td>Age group (y)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;25</td>
<td>68*</td>
<td>53*</td>
<td>12</td>
</tr>
<tr>
<td>25–34</td>
<td>53</td>
<td>39</td>
<td>12</td>
</tr>
<tr>
<td>≥35</td>
<td>31</td>
<td>23</td>
<td>15</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>61*</td>
<td>43*</td>
<td>12</td>
</tr>
<tr>
<td>Caucasian</td>
<td>74</td>
<td>71</td>
<td>9</td>
</tr>
<tr>
<td>Other</td>
<td>70</td>
<td>57</td>
<td>22</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>65</td>
<td>50</td>
<td>12</td>
</tr>
<tr>
<td>Previously married</td>
<td>52</td>
<td>35</td>
<td>11</td>
</tr>
<tr>
<td>Married</td>
<td>51</td>
<td>38</td>
<td>17</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;High school</td>
<td>65</td>
<td>53</td>
<td>14</td>
</tr>
<tr>
<td>High school graduate</td>
<td>61</td>
<td>46</td>
<td>10</td>
</tr>
<tr>
<td>Some college or better</td>
<td>65</td>
<td>46</td>
<td>13</td>
</tr>
</tbody>
</table>

* P<.05, between strata within each health state.


**TABLE 4**

Participant preferences for future infertility by pregnancy history.

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Sinus congestion</th>
<th>Chronic headache</th>
<th>Paralysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>63</td>
<td>48</td>
<td>12</td>
</tr>
<tr>
<td>No. of pregnancies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>78*</td>
<td>65*</td>
<td>19</td>
</tr>
<tr>
<td>1 or more</td>
<td>58</td>
<td>42</td>
<td>9</td>
</tr>
<tr>
<td>No. of children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>76*</td>
<td>62*</td>
<td>18*</td>
</tr>
<tr>
<td>1–2</td>
<td>59</td>
<td>44</td>
<td>8</td>
</tr>
<tr>
<td>3 or more</td>
<td>43</td>
<td>27</td>
<td>9</td>
</tr>
<tr>
<td>Infertility at 1-y follow-up</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>74*</td>
<td>63*</td>
<td>11</td>
</tr>
<tr>
<td>No</td>
<td>61</td>
<td>46</td>
<td>12</td>
</tr>
</tbody>
</table>

* P<.05 between strata within each health state.

participants rated future infertility as being worse than each of the seven comparative health conditions. Infertility was viewed as worse than even dialysis and paralysis in this group. At the other end of the spectrum, nearly 20% viewed infertility as an insignificant concern in comparison to the other conditions. These results, and the differences noted in the perception of infertility across countries shown in another report (23), suggest that it may be complicated to generalize infertility preference ratings across populations.

Future infertility ratings were also influenced by several demographic and pregnancy-related factors. Participants who were non-black, who had few children, who were unable to conceive, or who placed a strong importance on future pregnancy generally rated future infertility as being more significant in impact. Not surprisingly, though, the strongest factor influencing perceptions about future infertility appeared to be present-day infertility. Race, parity, and the importance of future pregnancy were only meaningful explanatory variables among women not currently experiencing infertility. This finding indicates that the views regarding future infertility vary strongly by the subjects’ previous exposure to infertility. Such an effect has been observed in studies on other health conditions, including cancer, in which persons with the condition rate the impact of the condition much differently than the general population (24, 25).

As noted, preferences for future infertility varied by race. This finding suggests that cultural differences may play a role in the assessment of the importance of future health. Although the racial group differences hold some statistical meaning in the comparisons tested, it is important to point out that large numbers of African-American women in the study still viewed the quality of life associated with infertility as a meaningful health issue.

The survey instrument used in this report represents a novel method for studying the value that women place on the ability to become pregnant. It asked the participants to choose their preference in paired comparisons between infertility and seven chronic health conditions, based upon short descriptions outlining the health consequences that are likely to be experienced with each condition. This method does not provide a direct assessment of the participants’ views regarding infertility. However, direct elicitation of the value of future infertility using the time-tradeoff or standard gamble approaches are not likely to provide meaningful results. Consider, for example, the ability to numerically quantify the tradeoff between immediate death and infertility (a common comparison used in other methods).

The goal of the paired comparison survey was to provide a meaningful and identifiable context to the relative importance assigned to infertility. The results can also be extended to address economic issues that consider priorities for infertility interventions relative to other health states. Infertility, though, remains a very complex health state, with physical, psychological, and lifestyle implications. The preferences stated by the participants may change with time and/or life events in the future.

Although the results of the study do not directly address patient behaviors, the stated perceptions regarding future infertility highlight two issues that are related to health care practice in PID and the access to fertility services. First, fertility preservation messages may be very important in campaigns to prevent PID. Second, the data suggest that there may be a strong demand for fertility services in the low-income and minority populations. These women, however, now face financial and insurance barriers to these services (11, 26). Interventions to address access to fertility services appear justified in this light.

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