

Assessing the emotional needs of women with spontaneous premature ovarian failure

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Objective: To examine women's emotional responses to learning the diagnosis of premature ovarian failure (POF) and identify the sources of support used for coping.

Design: Observational study.

Setting: National Institutes of Health Clinical Center.

Patient(s): One hundred women previously diagnosed with POF of median age 28 years at diagnosis.

Intervention(s): Structured telephone interviews based on focus group findings.

Main Outcome Measure(s): Manner informed of POF diagnosis, emotional response, and areas of emotional support.

Result(s): Overall, 71% were unsatisfied with the manner in which they were informed by their clinician, and 89% reported experiencing moderate to severe emotional distress at the time. The degree of emotional distress was positively correlated with the degree of dissatisfaction with the manner in which the women had been informed of the diagnosis. Thorough and accurate medical information on POF, support of others, and spirituality were perceived as helpful in coping.

Conclusion(s): Learning the diagnosis of POF can be emotionally traumatic and difficult for women. The findings suggest that the manner in which patients are informed of this diagnosis can significantly impact their level of distress. Patients perceive a need for clinicians to spend more time with them and provide more information about POF. (*Fertil Steril*® 2005;83:1734–41. ©2005 by American Society for Reproductive Medicine.)

Key Words: Premature ovarian failure, psychology, emotional needs, emotional response, coping, support, spirituality

Spontaneous premature ovarian failure (POF) involves the cessation of normal ovarian function before age 40, causing infertility, menopausal symptoms, and general health concerns. It affects approximately 1% of women (1). Although numerous studies are available on the pathophysiology of POF, remarkably little research is available on the psychological response to this disorder. Existing literature shows an association between POF and psychological distress, and suggestions have been made that psychological care should be included in its management (2). Qualitative research has revealed that POF often comes as a shock to young women,

and leaves most women feeling “out of synchrony” in their lives (3).

In general, the psychological distress of women with infertility has been well-documented in the literature as the inability to reproduce creates a profound loss for women, affecting their self-esteem and relationships with others (4–7). Most commonly, women discover that they are infertile in a gradual manner after many failed attempts at conception. However, in cases such as POF, medical conditions that preclude normal fertility can be uncovered during the course of investigation of other presenting complaints. Thus, the clinician is confronted with communicating information about a sudden, unexpected diagnosis that is life-altering but not life threatening. How bad news is communicated can have a profound effect on patient satisfaction (8, 9), treatment compliance (8), quality of life (10), and other health outcomes (11–19).

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Little is known about the unique emotional needs and responses of women who encounter the life-changing diagnosis of POF. Previously, it was reported that there was an association between the time women spent with their clinicians when informed of the POF diagnosis and their satisfaction with how they were informed (20). This study also noted that over two-thirds of the informing clinicians made no referral to additional sources of information or support for the disorder. It has been our clinical experience that a large number of women with POF who are seen at the National Institutes of Health (NIH) for evaluation complain that they have trouble finding information and support in dealing with this problem.

The present study sought to elaborate on previous findings by collecting data about the feelings of women with POF, particularly focusing on the transitional period after the women first learned of the diagnosis. The goal of this project was to learn more about the emotional processes associated with POF by [1] collecting evidence regarding the manner in which women were informed of the diagnosis; [2] assessing the initial emotional impact; [3] identifying areas of support used in coping; and [4] identifying factors that might improve care for women with POF.

MATERIALS AND METHODS

Patients

Patients with spontaneous POF were recruited through letters to clinicians and advertisements on the Internet. The institutional review board of the National Institute of Child Health and Human Development approved the study. All participants gave written informed consent. Infertility and amenorrhea were the major concerns of these patients, and they generally considered themselves to be otherwise in good health. Referring clinicians made the diagnosis of POF based on the development of at least 4 months of amenorrhea before age 40, associated with two serum FSH levels in the menopausal range (sampled at least 1 month apart). Women with POF as a result of surgery, radiation, chemotherapy, or known karyotype abnormalities were not included in the study to exclude confounding of the emotional issues by other medical conditions. Participants in the focus groups and structured interviews were informed that the purpose of the study was to learn more about the needs of young women with spontaneous POF.

Focus Groups

The study was divided into two parts. First, focus groups were conducted as an exploratory research technique to gain a qualitative understanding of the emotional aspects of POF, according to women who have POF. Focus groups are frequently conducted as part of a needs assessment to learn about a population's needs first hand. The results of the focus groups were used in the second part of the study to develop a structured interview examining the same issues on a quantitative basis.

Two focus groups were conducted at a professional focus group facility. Focus group participants were recruited from a pool of 27 women local to the Washington, DC, area who had received a prior diagnosis of POF before coming to the National Institutes of Health (NIH). The first focus group was composed of three women between the ages of 33 and 38 who had not participated in a POF support group. The second group was composed of five women between the ages of 33 and 42 who were actively participating in a support group. The women were divided in this manner to control for the degree of previous interaction with other women having POF. This was important because it was expected that women participating in the support group might have a higher comfort level when discussing issues pertaining to their POF diagnosis.

A professional moderator from ORC Macro (Calverton, MD) conducted the groups, employing a prospectively prepared moderator's guide designed to address the main research questions of: how the diagnosis was presented to participants, what their feelings were when they learned of the diagnosis, how the diagnosis impacted their lives at the time, and who they turned to for emotional support. The sessions were tape recorded and observed by the investigators through a one-way mirror.

Professional transcriptionists prepared the transcripts from the taped focus group sessions. One investigator coded the transcripts using a unique code for each question. The process was carried out manually, creating a document where quotes were sorted by the corresponding question or theme. Once the code document had been created, the other investigators reviewed these codes to come to an agreement. The content of the printed transcripts was then analyzed for consistent themes and trends in participant responses.

Structured Interview

Based on the findings from the focus group, a written script containing a total of 48 yes or no, multiple choice, and open-ended questions was prepared. The script was piloted on two women who had participated in the focus group study, and changes were made based on their suggestions. The questions focused on [1] the process of learning the POF diagnosis; [2] emotional responses and level of distress; and [3] emotional support and coping.

One investigator (A.A.G.) conducted all of the structured interviews by telephone. Of 101 women asked to participate in the structured interview, 100 women agreed to take part. These women had visited the NIH as patients between January 2000 and July 2003, and were contacted beginning with those who had come to the study most recently. Patients who could not speak English fluently were excluded from the list and were not contacted.

Analysis

We analyzed the data using a personal computer software package and computed descriptive statistics for the measures

(SigmaStat 2.0i; SPSS, Inc., Chicago, IL). For normally distributed descriptive data, we report mean \pm standard deviation. For other descriptive data, we report median, range, and percentiles. The 95% confidence interval (CI) of descriptive proportions was calculated according to the binomial distribution (21). For inferential analysis, the Fisher exact test assessed differences in proportions of categorical measures, and the Spearman rank order test was used to examine correlations. $P < .05$ was considered statistically significant.

RESULTS

Focus Groups

Participants reported having struggled with gaining understanding about the diagnosis of POF and with adapting their lives to the diagnosis. They associated the following feelings with first hearing about the diagnosis of POF: confusion, depression, anxiety, emptiness, loss, shock, anger, denial, relief (to know what is wrong), and curiosity.

When asked about support structures, most participants mentioned that problems in communications with their physicians had caused them a great deal of distress. They felt that many clinicians lacked knowledge, sensitivity, and helpful suggestions for dealing with POF. For example, one participant said, "I found out through my endocrinologist who diagnosed me with Hashimoto's and then did initial blood work, but he didn't actually know what to call what it was."

Women mentioned their main sources of social support were their mothers and husbands. There was a general sense that other women can relate better than men to the emotional aspects of POF. However, learning about the diagnosis had varying effects on participants' interpersonal relationships: it put strain on some relationships but improved other relationships by bringing women closer to people who were supportive of their needs. Women in the "support" focus group coped more by talking, and women in the nonsupport focus group coped more by dealing with the diagnosis privately.

A pertinent emotional need expressed by most participants was to have more information available about POF. The lack of available knowledge about POF seemed to decrease participants' sense of control, and therefore diminish their ability to function with the diagnosis. Participants in the nonsupport group mentioned keeping their feelings about POF a hidden part of their life, but members of the support group mentioned working to incorporate the diagnosis into their lives. For example, one participant in the support group said, "It was devastating. I also after a time came to see it as a challenge or a test. As something that might strengthen me."

Several participants indicated that having a diagnosis of POF had negatively affected their body image and their sense of age. For example, participants mentioned feeling less feminine and feeling older. One woman said, "It has been a real wake-up call for me that I am not young anymore."

When asked what the ideal support structure would contain, suggestions included a forum where women can meet with others with POF, a network of informed physicians, and a place where medical information is available.

Structured Interview

The median age of women who participated in the structured interview was 33 years (range: 21 to 43 years). The median age at the time of diagnosis was 28 years (range: 13.5 to 39.0 years). Most women had attended college (67%) and many had completed a graduate or professional degree (30%). One participant was Asian, five Hispanic, seven African American, and 87 Caucasian. At the time of diagnosis, the majority of women were married (62%) and had no children (81%), but had had future plans for children (93%). When this retrospective study was conducted, it had been a median of 3 years since participants received the diagnosis (range: 0.25 to 22.00).

Process of learning the diagnosis of POF. Most women reported having been initially informed of the diagnosis of POF by a gynecologist (50%) or a reproductive endocrinologist (28%). Some patients reported being informed by a medical endocrinologist (8%), a family physician (8%), internist (2%), and in one case a pediatrician; in three cases, the type of clinician could not be specified.

The self-reported characteristics of communication that informed women of the diagnosis of POF are shown in Table 1. Most women (53%) were informed of the diagnosis in an office setting, but a substantial proportion (43%) was informed by a telephone call, in many cases while at work. One woman was informed of the diagnosis by a message left on an answering machine and another by an e-mail correspondence. From an emotional perspective, 84% of the women felt they were unprepared to receive the diagnosis. Although many women (49%) described the informing clinician as sensitive to their emotional needs, an equal amount considered the clinician insensitive or very insensitive.

Of the women interviewed, 75% reported that the clinician spent 15 minutes or less speaking with them about their diagnosis, with over one-third of women (35%) recalling spending 5 minutes or less. Most (55%) thought the clinician should have spent more time with them and should have provided more information about POF. When asked to give an opinion of how knowledgeable the informing clinician was about POF, the majority (53%) believed that the physician had limited or very limited knowledge of POF.

Overall, only 25% of women were very satisfied or satisfied with how they were informed of the diagnosis, and fully 71% were unsatisfied or very unsatisfied. Women were statistically significantly more likely to be satisfied with the manner in which they were informed of the diagnosis if they felt they were prepared emotionally for the news (9 out of 14 vs 15 out of 81, $P < .001$), felt that the clinician spent enough time with them (23 out of 38 vs 2 out of 52, $P < .001$), and perceived the clinician as both knowledgeable (18 out of 43

TABLE 1

Characteristics of the communication that informed 100 women of the diagnosis of spontaneous premature ovarian failure (self-reported recall).

Characteristic	Proportion (95% confidence interval)
Setting	
Office visit	53% (43, 63)
At home by telephone	19% (12, 28)
At work by telephone	21% (14, 30)
Other	7% (3, 14)
Attention to emotional needs	
Very sensitive	12% (6, 20)
Sensitive	37% (28, 47)
Insensitive	31% (22, 41)
Very insensitive	18% (11, 27)
Other	2% (2/100)
Felt prepared emotionally	
Fully	2% (2/100)
Partially	12% (6, 20)
Unprepared	28% (19, 38)
Fully unprepared	56% (46, 66)
Other	2% (2/100)
Time spent in minutes	
More than 30	7% (3, 14)
30 or less, but more than 15	18% (11, 27)
15 or less, but more than 5	40% (30, 50)
5 or less	35% (26, 45)
Adequacy of time spent	
Yes, spent enough time	40% (30, 50)
No, should have spent more time	55% (45, 65)
Other	5% (2, 11)
Adequacy of information provided	
Yes, adequate information given	12% (6, 20)
No, should have been given more	86% (78, 92)
Other	2% (2/100)
Overall satisfaction with how informed	
Very satisfied	5% (2, 11)
Satisfied	20% (13, 29)
Unsatisfied	36% (27, 46)
Very unsatisfied	35% (26, 45)
Other	2% (2/100)

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TABLE 2

Self-reported emotional impact on 100 women given the diagnosis of spontaneous premature ovarian failure.

Factor	Proportion (95% confidence interval)
Emotional distress in first 2 hours after diagnosis	
Severe	58% (47, 65)
Moderate	31% (22, 41)
Minimal	8% (3, 15)
None	1% (0.03, 6)
Amount of suffering the diagnosis has caused	
Severe	35% (26, 45)
Moderate	49% (39, 59)
Minimal	15% (9, 24)
None	1% (1/100)
Feelings associated with the diagnosis	
Anger	81% (72, 88)
Depression	76% (66, 84)
Generally less healthy	74% (64, 82)
Emptiness	71% (61, 80)
Older	68% (60, 77)
Confusion	67% (57, 76)
Anxiety	63% (53, 72)
Altered self-image	63% (53, 72)
Less feminine	52% (42, 62)
Guilt	51% (41, 61)
Hopelessness	44% (34, 54)
Worthlessness	32% (23, 42)

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vs 6 out of 52, $P < .001$) and sensitive (18 out of 48 vs 6 out of 40, $P = .009$).

Emotional response to diagnosis of POF. The self-reported emotional impact of 100 young women given the diagnosis of spontaneous POF is shown in Table 2. Most participants (89%) recalled experiencing moderate to severe levels of emotional distress in the 2 hours following their diagnosis. When asked to describe using one or two words how they had felt immediately after hearing the diagnosis, the most commonly used word was “devastated” (25%), followed by “shocked” (20%). Emotional responses ranged from feeling anger (81%) and depression (76%) to feeling less healthy (74%), older (68%), and less feminine (52%). Most women (84%) reported that the diagnosis has caused moderate to severe emotional suffering. The degree of emotional distress reported was positively correlated with the degree of dissatisfaction with the manner women had been informed about the diagnosis ($r = .256$, $P = .01$).

Emotional support and coping. Most women (89%) reported that getting thorough and accurate information about POF helped them feel better emotionally. At the initial visit, most patients reported having had some discussion regarding a plan for managing the associated infertility (62%) and estrogen deficiency (70%) that accompanies a diagnosis of spontaneous POF (Table 3). However, a minority (41%) recalled having a discussion about other health risks associated with the diagnosis, such as hypothyroidism or adrenal insufficiency. Similarly, most (97%) had no recall of any discussion regarding a plan of management for the emotional and mental health aspects of POF, and few (8%) reported being referred to sources of emotional support such as a psychologist, social worker, clergy, or support group.

After being informed of the diagnosis, 92% of women discussed the diagnosis with a relative, partner, or close friend on the same day. In two cases, the first conversation with another was delayed until days later, in one case weeks later, and in three cases, months later. In two cases, women waited years before discussing the diagnosis with someone. Of married women, most (81%, 50 out of 62) discussed the diagnosis first with their husband, and 80% (40 out of 50) of these were satisfied with the emotional support and understanding that their husband provided. Most married women (63%) said that their husband was their most important source of emotional support and understanding. Unmarried women were most likely to tell their parents about the diagnosis (58%, 22 out of 38), particularly their mother (47%, 18 out of 38).

Only one-third of women reported seeking out professional help in dealing with the emotional and mental health aspects of POF, yet of those who did most (76%) found this to be helpful (Table 4). Nearly two-thirds of women with this diagnosis found their spirituality an important or extremely important source of strength and coping. A minority of women (20%) had been involved in a support group, and most who had been found this to be helpful (85%, 17 out of 20). Most women (80%) reported that meeting another woman with POF made them feel better emotionally. Before coming to the NIH Clinical Center, only 25% of women had met another woman with POF; by the time of the structured survey, 92% had done so. In addition, approximately one-half had communicated with other women with POF by e-mail or by an Internet chat site. Most (79%) found this to be helpful.

At the time of the interview, participants were asked, "Overall, when you are alone, how well do you feel that you are coping with having the diagnosis of POF?" Most responded that they were doing "very well" (33%) or "pretty well" (51%), and only 12% said "not very well." Two women indicated that the diagnosis is more than they can handle emotionally, and one woman reported that she was in denial and not coping. No statistically significant correlation was found between the initial satisfaction with the reported

TABLE 3

Medical management issues addressed at the time of diagnosis in 100 women with spontaneous premature ovarian failure (self-reported recall).

Medical management issue	Proportion (95% confidence interval)
Plan for infertility	
Provided	62% (52, 72)
Not provided	38% (28, 48)
Plan for hormone replacement	
Provided	70% (60, 79)
Not provided	29% (20, 40)
Unknown	1% (1/100)
Other health risks mentioned	
Yes	41% (31, 51)
No	57% (47, 69)
Unknown	2% (2/100)
Plan for other medical aspects	
Provided	27% (19, 37)
Not provided	73% (63, 81)
Plan for emotional and mental health	
Provided	2% (2/100)
Not provided	97% (92, 99)
Unknown	1% (1/100)
Referral for emotional support	
Provided	8% (4, 15)
Not provided	89% (81, 94)
Unknown	3% (3/100)

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manner in which they had been informed and with their present state of coping or stated degree of suffering.

DISCUSSION

Findings from the structured interviews with 100 women support the concerns expressed by the focus groups. Women diagnosed with POF report significant emotional distress on learning the diagnosis from their clinicians, and most feel they were given inadequate time, information, and preparation to cope. These quantitative findings support the focus group discussions that suggested many clinicians lack knowledge regarding POF and fail to recognize the emotional importance of the condition.

Most women in the study felt that their clinicians failed to present the diagnosis in the most effective manner and that they were not emotionally prepared to receive the diagnosis.

TABLE 4**Self-reported sources of emotional support sought out by 100 women given the diagnosis of spontaneous premature ovarian failure.**

Source of emotional support	Proportion (95% confidence interval)
Professional counseling	
Had counseling	33% (24, 43)
Found helpful	78% (60, 91)
Found not helpful	19% (7, 36)
Just started	3% (0.08, 16)
Did not have counseling	67% (57, 76)
Spirituality as a source of strength and coping	
Extremely important source	40% (30, 50)
Important source	25% (17, 35)
Limited source	25% (17, 35)
Not a source	10% (5, 18)
Support group	
Involved	20% (12, 28)
Found helpful	85% (62, 97)
Found not helpful	15% (3, 38)
Never involved	80% (71, 87)
Other women with premature ovarian failure	
Met another before NIH visit	25% (17, 35)
Met another at any time	92% (85, 96)
Extremely helpful emotionally	41% (30, 51)
Somewhat helpful emotionally	39% (29, 50)
Not helpful emotionally	18% (11, 28)
Made worse emotionally	1% (1/92)
Unsure	1% (1/92)
Communicated by email or chat site	52% (42, 62)
Extremely helpful emotionally	35% (22, 49)
Somewhat helpful emotionally	44% (30, 59)
Not helpful emotionally	17% (8, 30)
Made worse emotionally	4% (0.5, 13)

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When communicating “bad news” to patients, it is important to assess what impact the news is likely to have on the individual patient receiving the news. Buckman (22) developed a six-step protocol as follows:

- Get the physical context right.
- Find out how much the patient knows.

- Find out how much the patient wants to know.
- Share the information.
- Respond to the patient’s feelings.
- Plan and follow through.

Establishing how much the patient knows and how much the patient wants to know is part of the groundwork that must be laid to prepare patients to receive bad news. Once this is accomplished, to further prepare the patient, it is suggested that giving an indication that things are serious before giving the details is helpful, much like a “warning shot” (8, 22). These steps will help in preparing a patient emotionally to hear a difficult diagnosis.

The fact that over 75% of the patients in this study felt unprepared to hear the news suggests there is room for improvement in this clinical skill. The fact that over 40% of women were informed of the diagnosis of POF by telephone, with half of these women being at work, suggests that their clinicians underestimated the potential emotional significance of the news. Viewed in this light, it is understandable why nearly one-half of the women perceived the informing clinician as insensitive to their emotional needs. Delivering difficult news in a supportive manner by telephone is difficult.

The study clearly indicates that receiving the diagnosis of POF is emotionally traumatic for women. These women expressed distress, not only in the hours after speaking to their clinician and receiving the diagnosis, but also in the longer term with regard to suffering. The diagnosis also appears to negatively affect body image, with women describing feeling old, unfeminine, less healthy, empty, and worthless. Perhaps the diagnostic term premature ovarian “failure” reinforces this sense of defectiveness for women. Clinicians may want to consider using the term “ovarian insufficiency” when discussing this disorder, as has been used in the French literature (23).

Patients perceive a need for clinicians to spend more time when informing them of this distressing diagnosis. Ideally, the diagnosis and plan for management should take place during an office visit when sufficient time can be given to discuss the implications of POF. For many women, the most palpable concern will be infertility and the ability to have children. As described by focus group members, accepting the diagnosis involves a grieving process, and sufficient time needs to be given before considering reproductive treatment options, especially donor oocyte treatment.

Information and educational materials should be made available on both the medical and emotional aspects of POF as part of this visit. Those women who participated in support organizations found it helpful, and patients and their families need to be made aware of resources such as the POF support group (<http://www.POFsupport.org>) (24). Referral resources for professional counseling and/or spiritual guidance to assist in coping should also be provided. Although a minority of women in our study had used these support resources, those who did found them to be helpful. Thus,

patients need to be encouraged to consider using these resources to assist them in understanding and adjusting to the diagnosis of POF as well as in healing an altered self-image.

We expect that informing patients about the diagnosis of POF with the approach recommended by Buckman (22) would improve many of the parameters that we measured in this study. First, get the physical context right. When considering this diagnosis, schedule the patient to come back to the office for an unhurried appointment to discuss the laboratory results. Patients will appreciate getting this news in person and will benefit from the tangible support that can be provided by a caring clinician. The clinician might start the discussion by asking the patient to summarize her understanding of what laboratory tests have been done and why. Then provide a “warning shot” such as “I have some bad news for you that is difficult for me to tell you about. It has to do with your fertility and the functioning of your ovaries.” Then pause to await the patient’s response and invitation to proceed. This then might be followed up with a statement along the lines of “The laboratory results suggest that you have an unusual condition that causes the ovaries to stop working normally.” Then pause again and await a response and invitation to proceed. This iterative approach will permit the clinician at each step to gauge how much information the patient is ready to hear about. At the point where the patient expresses emotion about the diagnosis, the clinician should respond to the patient’s feelings and validate them, possibly by a statement such as “I understand how you feel. Most women find this diagnosis difficult to accept emotionally. I want you to know that we are in this together, and I am here to help you with this.” In some cases, emotions will take over; additional information is unlikely to be processed appropriately, and another follow up office visit will need to be scheduled. Clinical judgment plays an important role in making the determination if this is the case. When that point is reached, the clinician should inquire about what sources of emotional support the patient has available, and suggest additional avenues of support if appropriate.

The findings from this study are limited by its retrospective format. For example, we do not know how the clinicians perceived the situation when giving the diagnosis, or how an objective observer might have perceived it. It is possible that some clinicians were sensitive but women did not remember this because the news was so upsetting. Nonetheless, we would not expect recall bias to alter the fact that 40% were informed by the telephone, a finding that is of concern considering the amount of emotional distress these women describe after hearing the news. The small size of the focus groups and the convenience sampling method used in this study limit the ability to generalize study results. Patients who chose to participate in the NIH study may not be representative of the larger pool of women with POF. However, this participation bias is difficult to counteract, because women who are not concerned about their diagnosis may not be likely to seek out participation in such a study.

Our findings point to the need for more research in this area. It is important to examine in more detail the coping strategies used by women with this disorder, and determine in longitudinal studies which strategies are associated with better emotional well-being. Prospective interventional studies comparing support strategies are also important. It is hoped that results of this preliminary investigation will stimulate more research regarding the emotional needs of women with POF, not only at the time of diagnosis but long afterward. Further research is necessary to continue the process of identifying how best to assist these women.

Learning the diagnosis of POF can be emotionally traumatic and difficult for women. Academic medicine has recognized the need to teach the requisite skills for communicating bad news (25), but most of our patients were unsatisfied with the manner in which they were informed of their diagnosis. Our patients were significantly more likely to be satisfied with how they were informed of their diagnosis if they [1] felt better prepared to receive the news, [2] perceived the clinician as knowledgeable, [3] felt that the clinician spent sufficient time with them, and [4] felt that the clinician was sensitive to their emotional needs. One controlled study demonstrated that simple statements of concern that take very little time can go a long way in helping women see their clinician as more caring, sensitive, and compassionate (19). It is our hope that this study will assist clinicians in providing the information, resources, and understanding that women with POF need.

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