Women with spontaneous 46,XX primary ovarian insufficiency (hypergonadotropic hypogonadism) have lower perceived social support than control women

Susan A. Orshan, Ph.D., R.N., B.C.,[a] *June L. Ventura, B.A.,*[a] *Sharon N. Covington, M.S.W.,*[a] *Vien H. Vanderhoof, C.R.N.P.,*[a] *James F. Troendle, Ph.D.,*[b] *and Lawrence M. Nelson, M.D.*[a]

[a] Integrated Reproductive Medicine Unit, Intramural Research Program on Reproductive and Adult Endocrinology, and [b] Biometry and Mathematical Statistics Branch, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health, Bethesda, Maryland

Objective: To test the hypothesis that women with spontaneous primary ovarian insufficiency differ from control women with regard to perceived social support and to investigate the relationship between perceived social support and self-esteem.
Design: Cross-sectional.
Setting: Mark O. Hatfield Clinical Research Center, National Institutes of Health.
Patient(s): Women diagnosed with spontaneous primary ovarian insufficiency (n = 154) at a mean age of 27 years and healthy control women (n = 63).
Intervention(s): Administration of validated self-reporting instruments.
Main Outcome Measure(s): Personal Resource Questionnaire 85 and Rosenberg Self-Esteem Scale.
Result(s): Women with primary ovarian insufficiency had significantly lower scores than controls on the perceived social support scale and the self-esteem scale. The findings remained significant after modeling with multivariate regression for differences in age, marital status, and having children. There was a significant positive correlation between self-esteem scores and perceived social support in patients. We found no significant differences in perceived social support or self-esteem related to marital status, whether or not the women had children, or time since diagnosis.
Conclusion(s): This evidence supports the need for prospective controlled studies. Strategies to improve social support and self-esteem might provide a therapeutic approach to reduce the emotional suffering that accompanies the life-altering diagnosis of spontaneous primary ovarian insufficiency. (Fertil Steril® 2009;92:688–93. ©2009 by American Society for Reproductive Medicine.)

Key Words: Primary ovarian insufficiency, hypergonadotropic hypogonadism, premature ovarian failure, premature menopause, infertility, coping, perceived social support, self-esteem

Investigators from various disciplines have recognized the positive impact of social support on stress, the maintenance of health, and the restoration of well-being (1–10). Social support refers to the help that people receive from others. This includes the nontangible emotional support that makes a person feel loved and cared for and that bolsters a sense of self-worth, help through the provision of information as well as tangible help such as transportation or money (11). Evidence shows that patients with primary ovarian insufficiency have reduced self-esteem, increased shyness, increased social anxiety, and more symptoms of depression compared with control women (12). These factors would be expected to be barriers to developing and maintaining a robust social support network (13, 14).

Spontaneous primary ovarian insufficiency (also known as hypergonadotropic hypogonadism, premature ovarian failure, and premature menopause) involves the cessation of normal ovarian function before age 40. The condition is associated with amenorrhea, symptoms of estrogen deficiency, infertility, and general health concerns (15–17). It affects approximately 1% of women by age 40 (18). Many women with this condition experience intermittent ovarian function that may last for decades after the diagnosis. Pregnancy may occur in some women many years after the diagnosis (17, 19). Our preferred term for the condition is

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Reprint requests: Lawrence M. Nelson, M.D., National Institutes of Health, CRC 1-3330, 10 Center Drive, MSC-1103, Bethesda, Maryland 20892-1103 (FAX: 301-402-0884; E-mail: Lawrence_Nelson@nih.gov).

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"primary ovarian insufficiency" as first introduced by Fuller Albright in 1942 (20).

Most commonly, women discover that they are infertile in a gradual manner after many failed attempts at conception. In contrast, the acute discovery of infertility in cases such as primary ovarian insufficiency frequently occurs during the course of investigation of other presenting complaints such as amenorrhea (21–24). When asked in structured interviews to describe how they felt immediately after hearing the diagnosis the most commonly used words were "devastated" and "shocked" (24). The acute emotional response to the loss of fertility in this setting in some ways parallels the acute grief response to the death of a loved one (21). When viewed from this perspective it seems appropriate, as suggested by Greil, to consider patients who receive a diagnosis of primary ovarian insufficiency as entering into a "socially constructed life crisis" and in need of social support rather than having a "trait" that the individual carries like a label (25).

Suggestions have been made that psychological care should be included in the management of women with primary ovarian insufficiency and that clinicians should inquire about what sources of emotional support the patient has available and suggest additional avenues of support if appropriate (24, 26). Here we test the hypothesis that women with primary ovarian insufficiency score lower on a measure of perceived social support than control women, and we also examine the relationship between perceived social support and self-esteem.

MATERIALS AND METHODS

Patients

We recruited women with spontaneous 46,XX primary ovarian insufficiency by published advertisement and by 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 women, and they generally considered themselves to be otherwise in good health. Referring clinicians made the diagnosis of primary ovarian insufficiency.

We defined spontaneous primary ovarian insufficiency as the development before age 40 years of at least 4 months of amenorrhea or menstrual irregularity associated with two serum FSH levels in the menopausal range as defined by the individual local assay (sampled at least 1 month apart). Women with primary ovarian insufficiency as a result of surgery, radiation, chemotherapy, or known karyotype abnormalities were not included. All women underwent a complete history and physical examination and baseline clinical and laboratory testing as described elsewhere (27).

Controls

Control women were recruited by local advertisement and compensated according to National Institutes of Health guidelines. They were between the ages of 18 and 42 years and described themselves as healthy, free of chronic disease, not pregnant, and regularly menstruating (cycles between 21 and 35 days). Patients and controls were recruited concurrently. We made no attempt to match for demographic characteristics and planned to correct statistically for any differences that occurred by chance.

Instruments

To assess perceived social support we administered the Personal Resource Questionnaire 85, part 2 (PRQ85) (28–30). This is a 25-item self-report instrument. Respondents are instructed to indicate the degree to which they agree or disagree with a series of statements using a 7-point Likert scale. Statements include items such as "There is someone I feel close to who makes me feel secure" and "There are people who are available to me if I needed help over an extended period of time." Perceived social support is conceptualized in accordance with Weiss's multidimensional model of social support and includes the concepts of intimacy, social integration, nurturance, worth, and assistance (28, 29). Possible scores range from 25 to 175, with higher scores indicative of higher perceived social support. Content and construct validity of the PRQ85 has been established through correlation with measurement of related concepts (28, 31). Over the years, a compilation of multiple studies of adolescents and adults has revealed alpha reliability coefficients of approximately 0.90 (30).

To assess self-esteem we administered the Rosenberg Self-Esteem Scale, a self-administered instrument that measures global self-esteem (32). Respondents rate their level of agreement with each of 10 statements, such as "I feel that I am a person of worth, at least on an equal basis with others" and "I wish I could have more respect for myself." Possible scores range from zero (low self-esteem) to 10 (high self-esteem). Rosenberg reported a reproducibility coefficient of 0.92 (33). Among respondents with infertility, Mindes et al. reported coefficient alpha values for the Rosenberg Self-Esteem Scale to be 0.89 and 0.91 at two different time points (34).

Hypotheses

The a priori primary hypotheses to be tested were that, compared with healthy controls, women with primary ovarian insufficiency will report [1] lower perceived social support and [2] lower levels of self-esteem and that [3] in women with primary ovarian insufficiency, there will be a positive correlation between levels of perceived social support and self-esteem score.

Statistical Methods

We analyzed fully completed questionnaires only. We tested comparisons with the Wilcoxon rank sum, proportions by χ^2, and correlations with the Spearman rank order. $P<.05$ was considered statistically significant. We report results as mean (SD) or median (range).