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

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Abstract

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 (PRQ85), 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. In patients there was a significant positive correlation between self-esteem scores and perceived social support. We found no significant differences in perceived social support or self-esteem related to marital status, whether or not they had children, or time since diagnosis.

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CAPSULE

Strategies to improve social support and self-esteem may reduce the emotional suffering that accompanies the life-altering diagnosis of spontaneous primary ovarian insufficiency. Further investigation is indicated.

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.

Keywords

Primary ovarian insufficiency; hypergonadotropic hypogonadism; premature ovarian failure; premature menopause; infertility; coping; perceived social support; self-esteem

INTRODUCTION

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 non-tangible emotional support that makes a person feel loved and cared for and 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 to 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 “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 grief response to an acute 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 a “trait” that the individual carries as 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 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 NIH guidelines. They were between the ages of 18 and 42 years, 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 have 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 ten 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 ten (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: compared to healthy controls, women with primary ovarian insufficiency will report 1) lower perceived social support, 2) lower levels of

self esteem, and 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 Chi Square, and correlations with the Spearman Rank Order. We considered a p value of less than 0.05 as statistically significant and report results as mean (SD) or median (range).

RESULTS

Of 157 women with spontaneous primary ovarian insufficiency who participated in the study 154 fully completed the instruments. Of 65 control women 63 did so. Comparisons of demographic characteristics between patients and controls with complete data are shown in Table 1. The women with spontaneous primary ovarian insufficiency were on average 2.3 years older than controls, more likely to be married, and less likely to have children.

Women with primary ovarian insufficiency had significantly lower scores [median (range)] than controls on the perceived social support scale [152 (92 – 174) vs 156 (117 – 174), $p < 0.001$, Figure 1]. Women with primary ovarian insufficiency also had significantly lower scores than controls on the self-esteem scale [9 (0 – 10) vs 10 (7 – 10), $p = 0.002$, Figure 2]. The differences between patients and controls remained significant with regard to perceived social support and self-esteem after modeling with multivariate regression for differences in age, marital status, and having children. There was a significant positive correlation between perceived social support and self-esteem scores in patients ($r = 0.410$, $p < 0.0001$, Figure 3). No such correlation was evident in the control women ($r = 0.037$, $p = 0.77$). In women with primary ovarian insufficiency, neither perceived social support nor self-esteem scores were significantly correlated with the age at the time of diagnosis, time since diagnosis, age at the time of study, or country of origin. Also, in patients we found no significant differences in perceived social support or self-esteem scores related to marital status or whether or not they had children. There was a trend in patients toward higher perceived social support in married women ($p = 0.09$).

DISCUSSION

The personal loss that comes with a life altering diagnosis may induce emotional suffering associated with grief, stigma, and reduced self-esteem. We found that women with primary ovarian insufficiency have reduced perceived social support compared to normal control women. We also found that women with primary ovarian insufficiency have reduced self-esteem compared to controls and their level of perceived social support is positively correlated with a measure of self-esteem. It is noteworthy that our findings showed no ameliorating effect of having a child.

We are not aware of any prior controlled studies that examined the level of perceived social support in women with primary insufficiency, or, for that matter, in women with infertility in general. In an uncontrolled study of women attending a specialist infertility center for their first appointment Slade et al. found that higher levels of perceived social support were associated with significantly lower measures of infertility related distress, anxiety and depression (14). They also found that perceived social support showed greater predictive capacity than satisfaction with partner relationship. In a study of women undergoing their first *in vitro* fertilization treatment Verhaak et al. found that perceived social support was a protective factor in predicting the emotional response to unsuccessful fertility treatment (35).

Many women with primary ovarian insufficiency describe being informed about the diagnosis as similar to being informed about the death of a loved one. They describe loss, grief, depression, and emptiness as if mourning (21). In some cases the grief can be described as so deep and intense as to have similarities to actually mourning the sudden death of a child. It is from this perspective that the grief response to this diagnosis might be best viewed as a psychosocial transition in need of social support (25,36). In our clinical experience, the grief related to the diagnosis of primary ovarian insufficiency may continue for months, or years, or in some cases may even fail to resolve. Intense grief that negatively impacts psychological well-being and health over time qualifies as *complicated grief*, which involves despair, sadness, guilt, and avoidance of situations and people related to reminders of the loss (36–39).

Severely stressful life events are commonly associated with a “crisis of meaning” in which individuals search for a coherent narrative about the event and for a renewed purpose in life (40). In a previously published work, we demonstrated that women with primary ovarian insufficiency who scored higher on a measure of meaning and purpose also scored higher on a measure of functional well-being (41). Much grief research has focused on pathological outcomes of grief and has failed to recognize grief’s capacity for positive change and growth (36,38). In the grief transition, the individual is an active participant engaged in a gradual process of realization, change, and adjustment within a social context containing supportive resources. Individual vulnerabilities and strengths may account for variability in the grief transition (36,42). One large study of grieving parents found that meaning came from connections with people, activities, beliefs and values, and personal growth (43).

To some patients, the associated stigma may be a barrier to disclosure of the condition within their social support network, thus isolating them from potential sources of support (14). Cultural norms and values that encourage reproduction and celebrate parenthood can make childlessness a potentially stigmatizing status, which can have adverse effects on the identities and interpersonal relationships of couples (44). Goffman has defined stigma as a negative sense of social difference from others, a difference so outside the socially defined norm that it discredits and devalues the individual (45). Cross cultural study has defined the desire for children as the norm and infertility as stigmatizing (46,47). Furthermore, failure to disclose infertility might lead the members of the patient’s social support network to assume that she is voluntarily childless, which has also been shown to be stigmatizing (48). The constant vigilance that this secrecy requires may have significant psychological costs (14,49,50).

Similar to our finding with regard to self-esteem, Slade et al. found a significant negative relationship between stigma and perceived social support in women presenting for infertility treatment (14). These studies confirm that individuals seek social support less in situations that threaten self-esteem (13). Slade et al. also found that stigma was significantly positively correlated not only with symptoms of infertility related distress, but also with symptoms of anxiety and depression. In addition, for women with infertility the greater the disclosure of the condition to others the greater the general distress (14). Of particular interest was their finding that for women there was a significant pathway from infertility-related distress to generalized distress, whereas for men these were not directly related. This suggests that men may be better at keeping this distress relatively contained, and less likely to influence more general functioning (14). Social support may contribute to more successful psychological adjustment. However, it is important to recognize that social support members may also respond in a manner that is unsupportive or distressing (34,44,51,52).

In our published research findings, we have found that women with primary ovarian insufficiency commonly have feelings of anger at their health care providers for their perceived lack of quality care (21,23,24). Many patients experience a delay in diagnosis because their amenorrhea was not taken seriously as a disorder in need of evaluation (21,23). Further, once

the diagnosis was made correctly, reportedly their clinicians did not appear to appreciate all of the ramifications of the diagnosis or its emotional impact (21,24).

On average, the women in this study were approximately 40 months from the time of the diagnosis when we evaluated them. The fact that we found no correlation between measures of perceived social support or self-esteem and time since diagnosis suggests that these are relatively stable effects of the diagnosis. This suggests a need for interventions on the part of clinicians to improve emotional well-being in patients in whom they make a diagnosis of primary ovarian insufficiency (21,23,24). Clinicians themselves have the power to increase social support for these patients. They can create an environment in which women and their partners feel well supported in asking questions and are assured that their concerns are taken seriously. Also, referrals to mental health professionals, occupational therapists, clergy, and support groups can further expand their social support network. There may be a need to develop a cadre of nurse educators for primary ovarian insufficiency as has been done for diabetes (53,54).

There are study limitations. Since we did not sample the entire population of women with primary ovarian insufficiency it is possible that due to referral and acquisition bias only women with more significant emotional distress came to be studied. On the other hand, it is also possible that we failed to sample a larger group of women who were too depressed or anxious to come for evaluation. Also, in a cross-sectional study we are unable to determine if the lower self-esteem was a cause of the lower perceived emotional support, or if the lower support led to lower self esteem. It is also possible that both self-esteem and perceived social support are correlated with a third unrecognized factor.

Learning the diagnosis of primary ovarian insufficiency can be emotionally traumatic and difficult for women. We found that women with primary ovarian insufficiency score lower on a measure of perceived social support than control women, suggesting that women with primary ovarian insufficiency may be isolating themselves as a result of their diagnosis. Lower measures on self-esteem compared to controls may be a factor contributing to the lower perceived social support. This study provides cross-sectional data supporting 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 primary ovarian insufficiency. Further investigation is indicated. It is our hope that this study will alert clinicians and assist them in providing the information, resources, and understanding that women with primary ovarian insufficiency need.

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Figure 1. Comparison of perceived social support between control women and women with spontaneous 46,XX primary ovarian insufficiency as assessed by the Personal Resource Questionnaire 85 Part 2. Whiskers represent 10 and 90th percentiles and lines in the boxes represent median and inter-quartile range.

Figure 2.

Comparison of self-esteem between control women and women with spontaneous 46,XX primary ovarian insufficiency as assessed by the Rosenberg Self-Esteem Scale. Whiskers represent 10th percentiles and lines in the boxes from bottom to top represent lower interquartile range, median, and upper interquartile range.

Figure 3.
Correlation between perceived social support and self-esteem in women with spontaneous 46,XX primary ovarian insufficiency. Measures were assessed by the Personal Resource Questionnaire 85 Part 2 and the Rosenberg Self-Esteem Scale.

Table 1

Characteristics of women with spontaneous 46,XX primary ovarian insufficiency (POI) and normal volunteer women (NV). Values represent means (SD) or N (%) if indicated.

	POI (N=154)	NV (N=63)	P
Age	32.2 (4.9)	29.9 (7.0)	<0.01
Age at menarche	12.9 (1.8)	12.8 (1.2)	0.59
Married, N (%)	100 (64.9)	23 (36.5)	<0.001
Have children, N (%)	31 (20.1)	27 (42.9)	<0.001
Race/Ethnicity, N (%)			0.08
Black	17 (11.0)	9 (14.3)	
White	119 (77.3)	44 (69.8)	
Hispanic	10 (6.5)	1 (1.6)	
Asian/Pacific Islander	6 (3.9)	8 (12.7)	
Other	2 (1.3)	1 (1.6)	
Birthplace, N (%)			0.14
North America	135 (87.7)	50 (79.4)	
Other	18 (11.7)	13 (20.6)	
Age at diagnosis	27.4 (7.4)	N/A	
Time since diagnosis (months)	40.3 (50.8)	N/A	