

A New Approach to Primary Ovarian Insufficiency

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KEYWORDS

- Primary ovarian insufficiency • Premature ovarian failure • Premature menopause
- Infertility • Integrated care

KEY POINTS

- Most women with primary ovarian insufficiency come to clinical attention with oligo/amenorrhea. Take this sign seriously, evaluate it properly, and avoid delay in diagnosis.
- The proper laboratory evaluation of amenorrhea includes a pregnancy test, and if negative, measurement of serum FSH, prolactin, and thyrotropin.
- Women younger than 40 who have 4 months of oligo/amenorrhea and two menopausal serum FSH levels, 1 month apart, meet criteria for primary ovarian insufficiency.
- The indicated tests to determine the mechanism of the disorder include:
 - Karyotype analysis that counts 30 cells so as to uncover mosaic chromosomal abnormalities.
 - Testing for the *FMR1* premutation.
 - Measurement of adrenal antibodies by indirect immunofluorescence and 21-hydroxylase immunoprecipitation tests.
- Primary ovarian insufficiency is a life-altering diagnosis that is highly emotionally charged. Inform women in the office; be supportive and sensitive to their emotions.
- Primary ovarian insufficiency is more than infertility. Physical and emotional health need to be addressed before moving on to plans for creating a family.

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INTRODUCTION

Recently the National Institutes of Health convened a stakeholders meeting on primary ovarian insufficiency to explore ways in which to advance the field. The published report stressed the need for an integrative approach.¹ Women with primary ovarian insufficiency face the acute shock of the diagnosis; associated stigma of infertility; grief from the death of dreams; anxiety and depression from the disruption of life plans; confusion around the cause; symptoms of estrogen deficiency; worry over the associated potential medical sequelae, such as reduced bone density and cardiovascular risk; and the uncertain future that all of these factors create.^{2,3} Evidence supports a role for a collaborative care model as a method to improve medical outcomes, reduce costs, and to do so in a way that clinicians find satisfying.⁴⁻⁶ This approach should be combined with the development of a public health knowledge network on primary ovarian insufficiency.^{7,8} This knowledge network would form the central component of a community of practice for the condition.^{9,10}

The authors' research team now includes a reproductive endocrinologist, reproductive psychiatrist, medical endocrinologist, occupational therapist, recreational therapist, nutritionist, chaplain, and social worker. They have learned that they need to know the patient at a personal level to care for them appropriately. Before evaluation, all of their patients answer a series of questions in writing about themselves and how primary ovarian insufficiency has affected their lives (**Box 1**). The authors call this "The Patient Narrative" and share it in confidence with the entire team. This practice has changed their team dynamics and given greater meaning to their work.

For most women the infertility associated with the diagnosis is the most upsetting component of the disorder (**Box 2**).¹¹ However, primary ovarian insufficiency involves many aspects of a woman's life. It is a serious chronic disease that requires long-term management. Chronic illnesses change people's lives. Patients and their caregivers are abruptly confronted with a restricted and uncertain future. They also acquire

Box 1

Patient narrative questions for women with primary ovarian insufficiency to answer in writing

- a. What would you like us to know about you as a person?
- b. How would you like your life to change in the next six months?
- c. What are your aspirations for your life in the long term?
- d. What gives your life meaning and purpose?
- e. If nothing changed in your life right now what would that mean to you?
- f. What were your dreams about your future family life before you found out that you have primary ovarian insufficiency?
- g. How has primary ovarian insufficiency affected your life?
- h. Please give us an example of a difficult situation in your life from the past (other than your diagnosis of primary ovarian insufficiency) and explain to us how you coped with that.
 - i. How do you cope with the diagnosis of primary ovarian insufficiency?
 - j. What fears do you have about the diagnosis of primary ovarian insufficiency and how it will affect your future?
- k. What fears do you have about your visit here?
- l. Is there anything else that you want us to know about you?

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