Perceptions and Health-Seeking Behaviour of Two Young Women with Iatrogenic Premature Menopause

Ina S. Irabon, MD, FPOGS,FPSRM,FPSGE and Zenith DLT Zordilla, MD
Department of Clinical Epidemiology, University of the Philippines Manila

Background: Premature menopause is a frequently overlooked condition with significant morbidity without timely intervention.
Objective: This descriptive study explored the perceptions, concerns, and health-seeking behavior of two women diagnosed with premature menopause, regarding their illness.
Methods: Authors interviewed two nulligravid patients less than 30 years old diagnosed with premature menopause. Verbal consent was sought prior to the interview. An interview guide adapted from the Explanatory Model (Kleinman) to probe each patient's perceptions, concerns and health-seeking behaviour regarding PM was used. Data validation was immediately sought after the interview with each patient before analysis. Thematic analysis was used to explore the patients' perceptions (physical, psychological, and social effects of PM) and health-seeking behavior that resulted from these effects.
Results: Results showed that vasomotor symptoms, infertility, and treatment costs are important issues for these patients to help them undertsand their illness. The neglected role of physicians in fully disclosing the effects of the disease is highlighted in one patient that hindered her from making informed choices for treatment. The behavioural responses of these patients were influenced by the following factors: ability to make informed decisions over disease management, degree of disruption of activities of daily living, infertility, amount of social and financial support.
Conclusion: Looking at the underlying motivations of women diagnosed with premature menopause about their illness may help physicians better understand patients' circumstances, how it affects them and their families, and their expected recovery process.

Key words: health-seeking behavior, iatrogenic premature menopause

Introduction

Premature menopause is the cessation of regular menstrual periods, and development of menopause symptoms before the age of 40 years.[1] Two main symptoms occur in premature menopause: 1) debilitating vasomotor symptoms (hot flashes, irritability, mood swings) due to hypoestrogenic state, and 2) infertility. It affects approximately 1% of the female population of reproductive age.[2] Majority of premature menopause cases are caused iatrogenically, through chemotherapy, radiation, and surgery.

Premature menopause is often underdiagnosed and its management is very challenging. Prolonged hypoestrogenic states result to increased risk of long-term medical consequences such cardiovascular diseases, osteoporosis, cognitive impairment, sexual dysfunction, and reduced overall quality of life. Aside from physical symptoms, patients also have higher risks for depression, negative self-image, perceived stress and decreased sexual well-being.[2] These negative psychological effects are compounded by social stigma due to infertility. Nulligravid patients and their partners contend with intense feelings of grief and loss for the biologic children the couple were expecting from the union.[3]

Early and timely hormonal intervention (when not contraindicated) is crucial to delay the somatic complications. Presently, there are no established medical treatment options to "recover" reproductive functions. However, in 2009, a team headed by Barad and Gleicher[4] started a randomized clinical trial to investigate Dehydroepiandrosterone (DHEA) as treatment for premature ovarian failure. This was discontinued in 2011 due to low recruitment rate secondary to rarity of the condition and the increasing use of egg, ovary or embryo cryopreservation prior to gonadotoxic treatment. In 2008, a case series was published by Mamas and Mamas showcased 5 patients with premature menopause who underwent treatment with DHEA. All patients successfully became pregnant spontaneously using the same treatment protocol patient A was offered.[5]

Streamlining interventions to improve quality of life of these women must be anchored on a meticulous study on each patient's unique experience of the disease. Physicians' careful consideration of the costs is also vital for successful management.

The main objective of this study is to explore the perceptions and health-seeking behavior of PM patients regarding their condition. Interaction of these variables are illustrated in the conceptual framework. (Figure 1). The authors believe that the perceptions and health-seeking behavior of patients with PM are influenced by a myriad of factors, foremost of which are the socioeconomic factors such as the level of education and financial capability; another factor that plays a major role would be the patient's desire to have biological children, which is strongly depicted in our story; available health care options presented to the patient; severity of menopausal symptoms, especially vasomotor symptoms that affect the patient's activities of daily living; psychological effects of menopause, especially if the patient starts to form a negative self-image; financial costs which affects not only the patient but the whole family as well; and the stigma of infertility. The authors also note the different strategies patients

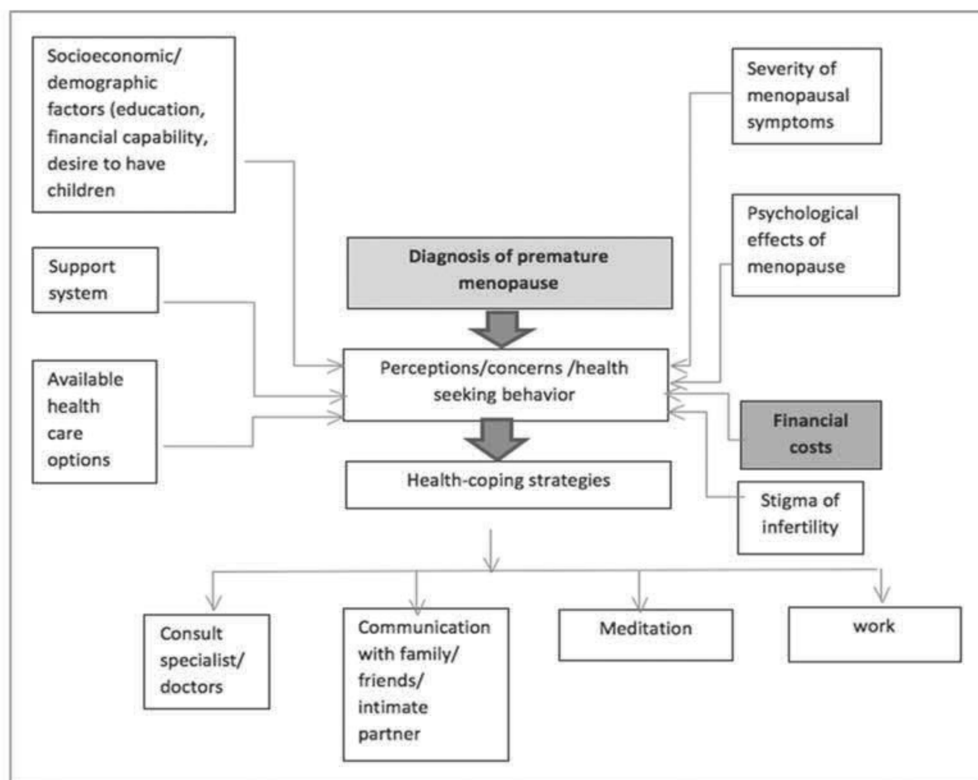

Figure 1. Conceptual Framework

do to cope with PM, such as consulting a specialist, communicating with the members of her social support group, meditation and occupying herself with work.

For this study, the authors laid out the operational definitions for the variables we used. Perception is defined as the way in which premature menopause is regarded, understood, or interpreted by their patients. Health seeking behaviour refers to the sequence of remedial actions that Patient A and B undertook to rectify their perceived ill health. This behaviour aims to achieve cure or control of illness. Concerns are matters that engage both patients' attention, interest, or care, or that affects their welfare or happiness.

Materials and Methods

A descriptive study was performed involving two conveniently-sampled patients with PM. The authors interviewed two nulligravid patients less than 30 years old diagnosed with PM. Verbal consent was sought prior to the interview. We used an interview guide adapted from the Explanatory Model (Kleinman) to probe each patient's perceptions, concerns and health-seeking behaviour regarding PM (Table 1). Data validation was immediately sought after the interview with each patient before analysis. Thematic analysis was used to explore the patients' perceptions (physical, psychological, and social effects of PM) and health-seeking behavior that resulted from these effects.

Table 1. Questionnaire based on Kleinman's Explanatory Model of Illness.

1. What do you think has caused your problems?
   "Ano sa palagay mo ang sanhi ng iyong karamdaman/ kondisyon?
2. Why do you think it started when it did?
   " Paano nagsimula ang iyong kondisyon?"
3. What do you think your sickness does to you? How does it work?
   "Ano sa palagay mo ang epekto ng kondiyon mo sa iyo?" Paano?
4. How severe is your sickness? Will it have a short or long course?
   "Gaano kalala ang iyong kundisyon? Gaano katagal kaya ito magtatagal?
5. What kind of treatment do you think you should receive?
   "Anong klaseng lunas ang kailangan mo, sa iyong palagay?
6. What are the most important results you hope to receive form this treatment?
   "Ano ang mga benepisyong gusto mong makamtam mula sa mga lunas na ito"
7. What are the chief problems your sickness has caused for you?
   "Anu-ano ang mga problema na dinulot ng iyong kundisyon?"
8. What do you fear most about your sickness?
   "Ano ang mga iyong kinatatakutan sanhi ng iyong kondisyon?

Results and Discussion

Patient Profile

A comparison of baseline characteristics is shown in Table 2. Patient A was diagnosed with large bilateral endometriotic cysts at 24 years old. She was advised surgery but she declined due to "fear of surgery". She then consulted a "medical oncologist" who guaranteed her "good and effective" results with intravenous (IV) chemotherapy even without surgical intervention to treat the ovarian cysts. She underwent 6 sessions of intravenous chemotherapy (unrecalled chemotherapy agents) financed by her parents and older brother. Funds for chemotherapy were mainly collected from selling their household possessions, land and carabao from the province. After just 3 cycles of chemotherapy, she has since been amenorrheic with severe bouts of vasomotor symptoms, such as severe hot flushes and night sweats. Her symptoms make it very difficult for her to do activities of daily living and perforn her work as an office assistant in her brother's office. Patient has plans of getting married to her intimate partner and is very desirous of pregnancy. Knowing about the consequences of her treatment has made her terribly regret blindly trusting her doctor's medical decision. She is currently seeking the help of an infertility specialist to remedy her situation.

Table 2. Baseline characteristics of two patients with premature menopause.

	Patient A	Patient B
Age at diagnosis of premature menopause	26 years	22 years
Gravidity	Nulligravid	nulligravid
Cause of premature menopause	Chemotherapy	Surgery and chemotherapy
Medical Diagnosis prior to intervention	Endometriotic cyst	Ovarian cancer stage 2
Current Symptoms	vasomotor symptoms	vasomotor symptoms
Access to gynecologic oncology care	None	Yes
Access to PhilHealth, HMO	None	Yes
Educational Attainment	HS undergraduate	College graduate
Employment	Employee at photo shop	Office worker / musician
Socio-economic Status of Family	low-income	middle-income
Support group	Family, intimate partner	Family, psychiatrist
Prior plans of having children	Yes	No

On consult, day 3 FSH of Patient A was 170 IU/ml. TSH and Prolactin levels were within normal results. Transvaginal ultrasound showed normal ovaries and uterus. She was maintained on hormone replacement therapy to relieve her severe vasomotor symptoms.

Patient B underwent total hystererectomy with bilateral salpingooophorectomy for malignant ovarian germ cell tumor stage II, financed by her parents. Although she was given the choice by her gynecologic oncologist to conserve her reproductive organs for fertility preservation, patient still opted for a radical surgery. This was due to her fear of recurrence and dying given her family history of malignancy. She is currently undergoing intravenous chemotherapy and is experiencing severe bouts of hot flushes. Her menopausal symtoms and chemotherapy prevents her from continuing office work and her musical pursuits. She developed depressive symptoms and was referred to a psychiatrist for co-management. Patient B claims that she is not desirous of pregnancy even prior to surgery and is not in a relationship as of the moment.

Thematic Analysis

Patient A and Patient B, despite their divergent backgrounds, etiology of illness, and treatments for premature menopause both have this motivation: the desire to retrieve their perceived loss from their illness: fertility for Patient A and former lifestyle for Patient B.

"...ang pinakamasakit isipin sa akin yung baka hindi na ako magkaanak dahil sa sakit ko. Pero naniniwala ako may paraan pa. Kaya nga ako lumapit na sa specialista. Hindi ko na kasi alam kung ano gagawin ko. Ayoko na magtiis sa sakit ko e. Gusto ko din malaman kung talagang may pag-asa pa ako magmens at magkaanak.Pwede nyo po ba ako matulungan pa magkaanak?" - Patient A

"I just wanna move on with my life...Im thankful for the second life I'm given.I'm thankful for my doctors for helping me cope... I wanna go back to my normal life na... mahirap lang talaga para saakin yung madalas na hot flushes kasi di ako masyado maka-work and makatulog." - Patient B

Patient's Perceptions About PM

Patient A initially identifies her premature menopause as something that hinders her ability to conceive children. It is her foremost concern. She has a burning desire to have biological children,

and she fears that her partner may break their engagement because of her infertility.

"Naiiyak ako syempre. Di ako makapaniwala pero may suspetsa na ako. Gusto ko sisihin sarili ko sa nangyari. Natatakot ako na di magkaanak. Baka hiwalayan ako ng boyfriend ko. Pero kinausap ko boyfriend ko, sabi naman nya na mag-ampon na lang kami kung talagang wala na pag-asa. Payag naman daw sya. Pero di ako sure. Baka iwan na nya ako..." - Patient A

Another concern for Patient A are her debilitating hot flushes, mood swings, and that significantly affected her daily activities, relationships with co-workers and family members.

"Mahirap magtrabaho kasi maya't maya inaatake ako ng init. Masakit din madalas ang ulo ko. Pero tinitiis ko lahat kasi nahihiya ako sa kuya ko." - Patient A

Patient A, from her diagnosis and throughout her treatment, denied being given a thorough explanation regarding her benign ovarian cyst by her physican. *She was also never given any alternative options other than chemotherapy*. She was completely unaware and unprepared for the onset of menopause resulting from chemotherapy in the last 2 years. Thus, when she sought the help of a reproductive endocrinologist and was formally diagnosed with "chemotherapy-induced premature menopause," she was in utter disbelief. She could not fully comprehend the possibility of menopause for someone as young as she is.

In contrast to Patient A, Patient B was fully informed about her condition *by a trained and competent gynecologic oncologist*. Her doctor dutifully discussed all treatment options available including the possibility of doing a conservative surgery to preserve her reproductive function. The adverse consequences of each treatment option was also fully explained to her. She also made her own research through the internet regarding her condition. Her doctor empowered her to make informed choices and participate in the decision-making process. But despite all these, she succumbed to episodes of depression. Her gynecologic oncologist referred her to a psychiatrist who Patient B claims helped her cope through the painful realization of her condition.

Patient B identifies her condition as something that is preventing her from working and from pursuing her musical career. Social stigma is not a concern, due to her positive outlook in life and a strong support system in the form of family, friends, and health care providers.

Perceptions, concerns, and health-seeking behavior of patients who are diagnosed with premature menopause are well-documented in various literature. Premature menopause is an event outside the normal life course and as such it is likely to have a significant impact on the quality of life, physical, emotional, and financial well-being of women who find themselves in this unfortunate condition. This study highlighted the role physicians play in shaping the perception of patients regarding their disease condition. This is a great opportunity for physicans to level the playing field given disparities on the socio-economic status, level of knowledge, and financial capability of patients with PM. This will serve as the foundation where patient may be empowered to make informed choices regarding their treatment. Empowered treatment decisions are vital to help patient cope with existential concerns about the future quality of life (ability to have children, relations with intimate partner), psychological distress due diagnosis and treatment, and body image threaten our patients' physical and psychological integrity.

Health-seeking Behaviour for Cure/Control of Illness

The health-seeking behavior of our patients were influenced by the following factors: perceived control over management of symptoms, severity of physical symptoms, degree of disruption of activities of daily living, infertility, and social and financial support.

Infertility was the greatest influence on Patient A's decision to seek medical care. After the initial shock and anger, patient A is now at the stage where she is willing (and desperate) to try treatment, even if her physician explained that the treatment

offers no guarantee for success, plus the high cost it would entail.

Her specialist would have recommended for her to see a psychiatrist for intervention. However, due to financial constraints, she opted to delay psychiatric consult and use her funds for hormone replacement treatment. Her specialist has been providing the patient with emotional support throughout her follow-ups. Her intimate partner has also been supportive and is open to the possibility of adoption. Her family is also helping her cope spiritually, emotionally and financially.

Patient B was better prepared to adapt to her condition. Patient B's journey to recovery has been supported by family and friends. Professional counselling by her psychiatrist is also instrumental in helping her cope with her condition. Her passion for music is something that she is able to look forward to even during chemotherapy. She has been allowed by her physician to continue with her nightly gigs as part of her recovery.

> *" Bata pa ako and I want to do everything possible to move forward with my life..ayoko na bumalik yung cancer.. alam ko naman lahat ng consequences ng desisyon ko" - Patient B*

The authors noted some of the health-coping strategies their patients take on in response to their medical condition. They saw the important roles of the specialist, their family, intimate partner, socioeconomic status and positive attitude to cope with their present problem. Herein now lies the crucial role of the specialist in finding a balance between tempering patient's expectations and at the same time trying to help her find "treatment."

Conclusion

PM patients perceive the loss of fertility and disruption of daily activities as main issues for their illness. Treatment of women with premature menopause requires early diagnosis, patient-specific, sensitive and sympathetic management of symptoms, and frequent counseling. Patients may be particularly sensitive to the following factors that could affect management: perceived control over management of symptoms, severity of physical symptoms, degree of disruption of activities of daily living, infertility, amount of social and financial support. Health seeking behavior is mainly affected by the severity of their symptoms, concerns on fertility and getting back to their "normal life"

The role of the health care provider is crucial for a patient with premature menopause. She must be very sympathetic and patient in explaining the patient's medical condition, putting into context the possible psychological unease the patient is currently in, and her fears and hopes. At the same time, the specialist should also manage patient's expectations, and make her realize her condition at the most pragmatic way possible, without pushing her to even deeper depression in the end.

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