Psychosocial Aspects of Premature Menopause

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The psychosocial issues faced by women with premature menopause are considerable and impact life plans and self-esteem. They include reactions to the diagnosis, concerns about health in the short- and long-term and reproductive capacity. In order to meet women's needs, healthcare systems should provide clear information, a range of treatments, psychological support and long-term follow up in multidisciplinary settings. A biopsychosocial approach that addresses women's psychosocial as well as biomedical needs is recommended.

The average age at menopause (commonly defined as 12 months after the cessation of menstruation) is 50.7 years;[1] it has remained relatively constant in the developed world. Menopause is considered premature when it occurs in women age 40 or younger, and is estimated to affect approximately 1% of women.[2] Age at menopause has been found to vary between countries and ethnic groups;[3] for example, in studies of women living in India and Pakistan the average age at menopause is 47 years, compared to 50–51 years in European and North American studies.[4] Premature menopause also can affect women in their 20s and 30s and, as the cure rates of cancers in young women continue to improve, it is likely that the incidence of premature menopause will rise rapidly.[5,6]

Psychosocial Impact

The psychosocial impact of premature menopause and women's quality of life in both the short- and long-term have been neglected by both clinicians and researchers.[2] Few studies have been carried out using standardized measures, but the available evidence suggests that women who have experienced premature menopause have high levels of depression and lower levels of self-esteem and life satisfaction when compared to those who have not.[7] Not surprisingly, it is the younger women and those who received the diagnosis more recently who are more likely to be depressed. Data from an interview study of 100 prematurely menopausal women[8] and a detailed qualitative study of 13 women[9] suggest that the causes of distress are complex and multidimensional; they include the diagnosis and how it is communicated, and being faced with issues that otherwise might not be considered until later in life (aging, long-term physical health, medical treatment). Fertility is a profound concern for those who have not had children, affecting expectations and choices for the future, as well as identity and social roles. Moreover, the largely negative social and cultural meanings of menopause present these younger women with additional challenges to their self-esteem, placing them in an often isolated and deviant position from that of their peers.[9]

Diagnosis: Impact and Style of Communication

The causes of premature menopause are commonly understood as either natural (being related to genetic conditions such as Turner's syndrome or autoimmune disorders)[10,11] or iatrogenic (induced by medical intervention including surgery, chemotherapy or radiation); for an estimated 90% of women, the exact cause is, however, unknown.[3] Obtaining a clear diagnosis can take several attempts. For example, 50% of women with secondary amenorrhea might see three or more clinicians before any laboratory testing to confirm the diagnosis is performed, and delay between first presentation and diagnosis may take between 1 and 5 years.[12]

Women's accounts of receiving a diagnosis of premature menopause suggest that it is nearly always experienced as a traumatic life event.[9] This is compounded by the time taken until diagnosis is established, increasing anxiety and uncertainty, dissatisfaction with the way diagnosis is communicated and the paucity of age-appropriate information. Women have reported that distress was consistently underestimated by their physicians and that information about premature menopause did not meet their needs.[7,9] Similarly, Groff et al[8] found that 89% of prematurely menopausal women interviewed reported experiencing moderate to severe emotional distress at the time of diagnosis, and 71% were dissatisfied with the manner in which they were informed by their clinicians; the degree of distress was directly associated with the degree of satisfaction with the manner in which they were informed.

Women's emotional reactions to a diagnosis of premature menopause have been described as similar to bereavement. There is often initial disbelief and self-blame when searching for explanations, and ambivalence about what terms to use to describe a condition that is invisible to others. Singer and Hunter[9] found that women described feeling abnormal and misunderstood, and when asked how they explained their diagnosis to others, many preferred to speak of "hormone imbalance" or "infertility" rather than using the term "menopause." One woman in this study explained, *"I always worry about how other people will react. I'm quite cool about telling people about my tumour, but with the menopause I feel embarrassed."* A diagnosis can, however, also provide relief, bringing an end to a long period of uncertainty.

Health Concerns

Long-term exposure to low estrogen levels can have a major impact upon the health of women with premature menopause; if untreated, the condition carries potential long-term health risks, such as cardiovascular disease, osteoporosis and fracture.[13,14] Typically, "hormone therapy" (HT) is now the preferred terminology when referring to therapeutic options for menopausal women, but for premature menopause the term "hormone replacement therapy" (HRT) is considered to be more appropriate; there is now general consensus that HRT should be offered to prematurely menopausal women up to age 50 (Table 1 lists resources for further guidance). HRT is recommended for prevention of these longer-term health risks and as a treatment for menopausal symptoms—hot flashes and night sweats—as well as vaginal dryness and related sexual difficulties. There is, however, concern that young women may not attend clinics regularly or may be lost to follow-up.[2] Furthermore, since the controversy regarding the safety of HRT following publication of the Women's Health Initiative and the Million Women Study, only 44% of women with premature menopause have been found to be aware that the results did not apply to their age group.[2] This can be a disadvantage to women who may be left without estrogen for 15 years or longer than their peers, with attendant medical sequelae.[14] HRT is also contraindicated for some prematurely menopausal women; for example, treatment of those also suffering from breast cancer often remains complicated, and non-hormonal alternatives need to be considered.[15]

Fertility

Loss of fertility is typically seen as the most distressing aspect of premature menopause.[7,9] The likelihood of spontaneous recovery of ovulation for women who have premature ovarian failure, rather than surgical menopause, has been estimated as approximately 5%–10%[3] and, as yet, is difficult to predict accurately. Donor egg in vitro fertilization and embryo transfer using donor oocytes have demonstrated reasonable success rates.[16] Cryopreservation of ovarian tissue prior to chemotherapy or radiation therapy is currently being investigated for women with induced premature ovarian failure. Although cryopreservation of human embryos has been possible since 1983, cryopreservation of ovarian tissue, or "egg-freezing," is now becoming an option for women who have induced menopause due to surgery, chemotherapy or radiotherapy. This form of treatment has the advantage that large numbers of gametes can be stored without delaying oncology treatment. While still technically considered experimental, recent advances in technology suggest that egg-freezing is likely to provide increased options for women in the future.[2,3] Adoption is an additional family-building option, and careful

Table 1. Early Menopause Resources

Early Menopause Resources
Early Menopause Guidebook, 2006, is available on The North American Menopause Society Web site: http://www.menopause.org/edumaterials/earlyguidebook.aspx
International Premature Ovarian Failure Association: http://pofsupport.org
The Daisy Network: http://www.daisynetwork.org.uk
The Jean Hailes Foundation: http://www.jeanhailes.org.au

counseling over a period of time is needed for couples to make informed choices. While family-building options can mitigate the loss of fertility to some degree, the stresses and strains of these options themselves suggest that guidance and counseling should be a central part of the process.

Infertility is often described as a major life event that compels a re-evaluation of one's sense of self, one's relationships and, for many women, a loss or challenge to a major life goal.[9,17] A grief reaction is common, with feelings of loss, shame, loss of self-esteem and, sometimes, relationship difficulties. Women with premature menopause and related infertility have described feeling "incomplete" and, therefore, of less value. Loss of reproductive capacity or lost life plans can leave women feeling powerless, feelings that may be aggravated by having to account publicly for this condition.[9] Being near or hearing about other people's children may be painful, leading to avoidance and isolation. Couples may benefit from support during this phase, as it can be a strain on both partners and the relationship. For example, each partner might express her/his distress in different ways, and therefore might not understand the other person's reactions or perspective, or they might avoid discussing the topic altogether to avoid distressing one another. In this context, communication and sexual problems are not uncommon.

For some women concern about fertility may arise several years following the original diagnosis; for instance, if or when they are ready to have children, or when close friends or relatives achieve a pregnancy. Even if women do not want to have children, having the choice taken away can also feel unjust. For a younger woman without a partner, anxiety may be expressed about how and when to tell a potential partner about the condition, because she might believe that she will be rejected if her menopausal or fertility status is known. Discussion with women who have gone through the experience, one-on-one and in support groups, can be useful. Counseling should be offered to couples dealing with fertility problems. On the positive side, women and couples do tend to make adjustments over time and often eventually find benefits in different activities and lifestyles.

Sense of Self

Premature menopause presents a woman with a potential threat to her sense of self or identity as a woman; in most cultures this involves a challenge to her sense of femininity, sexuality and her potential social roles as mother and grandmother. Certainly in Western cultures, where youth and beauty are idealized, incorporating the idea of menopause into one's self-concept as a young woman can be very difficult. Along with the physical and practical changes, such as hot flashes, infertility and hormonal therapy, women also are confronted with the social and cultural meanings of menopause—negative meanings that in many cases exacerbate the situation, leading to additional and unnecessary distress.[9,18] Young women have reported feeling abnormal, feeling that they were not "real women," and feeling unattractive, "asexual" and old beyond their years.[9] The idea of rapid aging has been commonly expressed by women with premature menopause, with fears of wrinkles, physical and emotional decline, aging overnight and even mortality. A major task in terms of accepting themselves as menopausal and maintaining a positive self-image can lie in the gulf between how women feel about themselves and the negative, stereotypical image that they hold or are aware of. *"I thought it meant getting fat, going grey. Now I realize it can happen to anybody, any age."*[9]

These beliefs can have a negative impact on self-esteem and should be challenged. Women can be helped to maintain a sense of self by slowly dealing with each issue in turn, with social support, clear information and multidisciplinary health care.

Facilitating Adjustment to Premature Menopause

When an unexpected event occurs it can turn beliefs and assumptions about one's self, the world and others upside down and result in uncertainty, low self-esteem and, sometimes, hopelessness. The task is to gradually assimilate new information into pre-existing beliefs and values.[19] Adjustment can be facilitated by having clear information, the opportunity for discussion and social support (Table 2). Social support enables normalization and confirmation of adaptive beliefs, and provides the opportunity to challenge unhelpful assumptions and overly negative beliefs and to reduce isolation. Support groups and websites can be helpful in providing informational, emotional and social support.[20]

While emotional reactions are normally experienced, moderate to severe anxiety or depression that does not remit may require psychological interventions such as cognitive behavior therapy or medication. Self-blame and guilt are common reactions, but if intense they are associated with low self-esteem and depression, and blaming others can lead to chronic anger and bitterness. It can be helpful to strike a balance and to focus on one issue at a time. Counseling and psychological therapy can help to challenge overly unhelpful beliefs such as, "if I'm infertile I will be unlovable," or "if I have premature menopause I will be old and unattractive." A focus on women's strengths and competencies,

Table 2. Issues to Cover when Counseling Women about Premature Menopause

Diagnosis: Detailed information, opportunity for discussion, provide resources
Health concerns: Short- and long-term (e.g., osteoporosis, additional health problems)
Lifestyle: Diet, exercise, smoking, alcohol, social support
Mood and emotional reactions: Provide opportunity to discuss the woman's reactions and offer additional support (e.g., bibliography, Web sites, counselor or psychological therapy)
Sexual health and concerns
Fertility issues: Information and options for the future
Treatment: Information and advice about HRT and alternatives
Follow-up: Offer follow-up appointments to monitor needs for information, treatments and support

as well as encouraging engagement in pleasant activities, is likely to increase self-esteem.[21]

Multidisciplinary Management

There is now a general consensus that women with premature menopause should have access to a multidisciplinary clinical team in order to address their physical and psychosocial needs;[2,3,21] this is not, however, always achieved in practice.[8] Health professionals should be available to provide diagnostic investigations, counseling, diet and nutritional advice and advice about HRT and its alternatives, as well as sexual health care, including that related to contraception and fertility issues.[2] Women should be encouraged to take a friend, relative or partner to consultations, not only for support but to develop a shared understanding. Anxiety and distress can impair attention and memory during a consultation, so that information may need to be repeated, summarized and made available in written form. Regular long-term follow-up and review is essential to meet the patient's needs related to physical health care and fertility issues, and particularly to address the range of psychosocial issues that arise across the lifespan. The challenge lies in finding ways of providing broad-ranging services without reinforcing negative feelings of difference, isolation or abnormality. Teaching and training for health professionals is a priority in order to improve women's experience of consultations and to encourage a biopsychosocial approach to the care of women who have experienced premature menopause.[21] ■

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