Maturitas 107 (2018) 44–49

Contents lists available at ScienceDirect

Maturitas

journal homepage: www.elsevier.com/locate/maturitas

Review Article

Data Registry on Experiences of Aging, Menopause, and Sexuality (DREAMS): A cohort profile

Stephanie S. Faubion[a,*], Ekta Kapoor[a,b], Juliana M. Kling[h], Carol L. Kuhle[a], Richa Sood[a], Jordan E. Rullo[a,c], Jacqueline M. Thielen[a], Lynne T. Shuster[a], Walter A. Rocca[d], Karla S. Frohmader Hilsaca[e], Kristin C. Mara[f], Darrell R. Schroeder[f], Virginia M. Miller[g]

[a] Women's Health Clinic, Division of General Internal Medicine, Mayo Clinic, Rochester, MN, United States
[b] Division of Endocrinology, Diabetes, Metabolism, and Nutrition, Mayo Clinic, Rochester, MN, United States
[c] Department of Psychiatry and Psychology, Mayo Clinic, Rochester, MN, United States
[d] Division of Epidemiology, Department of Neurology, Mayo Clinic, Rochester, MN, United States
[e] Division of General Internal Medicine, Mayo Clinic, Rochester, MN, United States
[f] Division of Biomedical Statistics and Informatics, Mayo Clinic, Rochester, MN, United States
[g] Women's Health Research Center, and Department of Physiology and Biomedical Engineering, Mayo Clinic, Rochester, MN, United States
[h] Division of Women's Health Internal Medicine, Mayo Clinic, Scottsdale, AZ, United States

ARTICLE INFO

Keywords:
Aging
Cohort study
Female sexual health
Menopausal hormone therapy
Menopause

ABSTRACT

The Women's Health Clinic (WHC) at Mayo Clinic in Rochester, Minnesota, has provided consultative care to women with menopausal and sexual health concerns since 2005. Clinical information on the 8688 women seen in the WHC through May 2017 who gave consent for the use of their medical records in research is contained in the Data Registry on Experiences of Aging, Menopause, and Sexuality (DREAMS). Initially, DREAMS was created to improve the clinical care of women, but it has become a valuable research tool. About 25% of the DREAMS women have been seen in the WHC 2 or more times, allowing for passive longitudinal follow-up. Additionally, about 25% of the DREAMS women live in the 27-county region included in the expanded Rochester Epidemiology Project medical records linkage system, providing additional information on those women. The cohort has been used to investigate associations between: caffeine intake and vasomotor symptom bother; recent abuse (physical, sexual, verbal, and emotional) and menopausal symptoms; specific menopausal symptoms and self-reported view of menopause; and obstructive sleep apnea risk and vasomotor symptom severity and the experience of vasomotor symptoms in women older than 60 years. A study nearing completion describes a clinical series of over 3500 women presenting for sexual health consultation by sexual function domain and by decade of life. Other studies under way are determining correlates with sexual health and dysfunction. Planned studies will investigate associations between the experience with menopause and the risk of disease.

1. Introduction

The Women's Health Clinic (WHC) at Mayo Clinic in Rochester, Minnesota, was established in July 2005 as a consultative practice specializing in the management of menopause and female sexual health concerns. At that time, the status and safety of menopausal hormone therapy were uncertain. The results of the Women's Health Initiative trials had been published in 2002, and subsequently, women had difficulty obtaining prescriptions for menopausal hormone therapy or were seeking alternatives. Furthermore, gaps existed in the treatment of sexual health concerns of women, who not uncommonly also had menopausal symptoms. The WHC was established to address these unmet clinical needs. A data registry of women seen for consultation was established concurrently with the WHC and subsequently named the Data Registry on Experiences of Aging, Menopause, and Sexuality (DREAMS). Although the initial use of the registry was to inform and improve clinical care, the registry also provided research opportunities.

Understanding the health and well-being of midlife women is critical for providing individualized care to women as they age. This focus is particularly salient with the increased life expectancy for women [1],

Abbreviations: ACE, adverse childhood experiences; BOSS, big one-stop shop; DREAMS, Data Registry on Experiences of Aging, Menopause, and Sexuality; FSFI, female sexual function index; MHQ, menopause health questionnaire; OSA, obstructive sleep apnea; REP, Rochester epidemiology project; VMS, vasomotor symptom; WHC, Women's Health Clinic

* Corresponding author at: Women's Health Clinic, Division of General Internal Medicine, Mayo Clinic, 200 First Street SW, Rochester, MN 55905, United States.
E-mail address: faubion.stephanie@mayo.edu (S.S. Faubion).

http://dx.doi.org/10.1016/j.maturitas.2017.09.013
Received 7 September 2017; Received in revised form 27 September 2017; Accepted 29 September 2017

Questionnaire	Period When Questionnaire Was Administered			
	July 2005-April 2015	May-December 2015	January-December 2016	January-May 2017
Menopause Health Questionnaire (MHQ)[a]	Only women referred for menopause consultation			
Female Sexual Function Index (FSFI)[a,b]	Only women referred for sexual health consultation	All women		
Menopause Rating Scale (MRS)[a,b]		All women		
Kansas Marital Satisfaction Scale[a,b]		All women		
Female Sexual Distress Scale—Revised (FSDS-R)[a,b]		All women		
Alcohol Use Disorders Identification Test (AUDIT)[a,b]		All women		
Patient Health Questionnaire depression scale (PHQ-9)[a,b]		All women		
Generalized Anxiety Disorder (GAD-7)[a,b]		All women		
STOP-Bang Questionnaire[a]		All women		
Adverse Childhood Experiences (ACEs)[a]		All women		
Gratitude Questionnaire (GQ-6)[a]		All women		
Mindful Attention Awareness Scale (MAAS)[a]		All women		
Perceived Stress Scale (4-item version) (PSS-4)[a]		All women		
Pittsburgh Sleep Quality Index (PSQI)[a]				All women
Brief Resilience Scale (BRS)[a]				All women
Perceived Stress Scale (10-item version) (PSS-10)[a]				All women
Linear Analogue Self-Assessment (LASA) of quality of life (single item)[a]				All women

Fig. 1. Timeline for Administration of Questionnaires. Footnote *a* indicates that questionnaire was administered to all women seen for initial consultation and annually to those returning for clinical care. Footnote *b* indicates that questionnaire was administered to all women seen for subsequent visits (> 2 weeks and < 1 year since the initial or annual visit). STOP-Bang indicates Snoring? Tired? Observed? Pressure? Body mass index > 35? Age > 50? Neck size large? Gender male?

because one-third of a woman's life may occur after menopause [2]. The menopausal transition—a normal physiologic change for most women—is nothing short of a sentinel event marking the loss of ovarian follicular function and the beginning of the postmenopausal phase [3]. It is an opportunity to assess the risk of diseases highly prevalent in postmenopausal women, to review preventive strategies, and to provide counseling and education to women with the goal of reducing the burden of chronic diseases of aging, especially cardiovascular disease [4]. Evidence is accumulating related to sex-specific differences in cardiovascular disease risk and the associations between factors such as polycystic ovary syndrome, diseases of pregnancy (eg, gestational diabetes and preeclampsia), natural and iatrogenic premature menopause, and the timing of the onset and persistence of vasomotor symptoms (VMSs) and future cardiovascular disease [5–11].

Identifying factors in midlife (or earlier) that predict sex-specific risk for disease may allow for more effective screening and prevention strategies. For example, hot flashes and night sweats (VMSs) are the most common symptoms experienced by women in the menopausal transition. Previously considered an annoyance to be endured, VMSs are now known to vary among women in the timing of onset and the duration and, in some women, to indicate neurovascular dysregulation and be a predictor of cardiovascular disease risk [9,12,13]. In addition, research is only beginning to unravel associations among stress, resilience, mood, sleep, obesity, substance use, abuse history, and the menopausal experience.

Female sexual dysfunction, another common concern in midlife women, is underdiagnosed and undertreated even though it seriously affects a woman's quality of life and well-being [14–16]. The compelling need for future research to guide the diagnosis and management of female sexual dysfunction cannot be overemphasized.

Because knowledge relating to the care of midlife women is limited, well-designed observational studies can provide invaluable information to address clinical questions that cannot be addressed through randomized controlled studies. In addition, observational studies may provide preliminary data for the design of randomized controlled clinical trials (when they are possible) to address treatment interventions and efficacy.

2. Who is in the cohort and what information is collected?

At the WHC, one of the largest menopause and women's sexual health clinics in the United States, about 2000 unique patients are seen