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Midlife Women's Symptom Cluster Heuristics: Evaluation of An iPad Application for Data Collection

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Abstract

Objective—To elicit midlife women's heuristics about symptom clusters they were experiencing as identified by the Computerized Symptom Capture Tool for menopause (C-SCAT M).

Methods—Women aged 40–60 years experiencing symptoms they associated with menopause were recruited through flyers posted on campus and in clinics. Women completed the C-SCAT M app using an iPad by identifying and drawing the symptom clusters they experienced during the last 24 hours, indicating relationships among symptoms, prioritizing the clusters and symptoms within them, and describing their causal attributions, and exacerbating and ameliorating factors. They were asked to prioritize the clusters and a symptom within each cluster. While completing the app, women were asked to “think aloud” about their experience using the app. Data generated from the C-SCAT M application were transmitted securely to an Amazon Web Services account and saved as screen images and Excel files to preserve both the graphical images and text elicited from the application. Qualitative data were saved in verbatim phrases. Conventional content analysis was used to analyze qualitative data.

Results—Thirty women completed the application. Most women (77%) stated that the final diagrams were very/extremely accurate in depicting their symptoms and their connections. Women reported between 1 and 22 symptoms (median 11). Hot flashes, waking up during the night, night sweats, and early morning awakening were the most commonly reported symptoms.

Women rated hot flashes as their most bothersome symptom, followed by waking up during the night and fatigue. They reported over 300 different bivariate relationships between their symptoms and over 150 unique causal paths. They believed that hot flashes caused several symptoms, especially sleep disruption, and most could describe the time order of their symptoms. Women reported clusters consisting of 2 to 18 symptoms. Women also named each cluster based on their response to their symptoms (“really annoying”), the time of occurrence (“night problem”), and symptoms in the cluster (“hot flash”). They attributed their clusters to menopause, life demands, and other symptoms, among other causes. Management strategies that women used included: over the counter preparations, sleep, rest, and other lifestyle changes. Some women requested a copy of their final symptom cluster diagram to discuss with their health care providers.

Conclusion—Using the C-SCAT M afforded women an opportunity to depict their symptoms and clusters and relationships between them, as well as to provide narrative data about their heuristics. Women’s unsolicited comments about using the cluster diagram to facilitate conversation about their symptoms with their health care providers suggest the potential value of modifying the C-SCAT M and evaluating its use in a health care setting.

Keywords

symptoms; symptom clusters; menopause; heuristics

Growing awareness of women’s experience of multiple co-occurring symptoms during the menopausal transition and early postmenopause provides impetus for research about symptom clusters women experience during this part of the lifespan.^{1–6} Symptom clusters consist of multiple symptoms that co-occur and may be related to one another through a common mechanism or etiology, a common shared variance, or the production of different outcomes than associated with individual symptoms, e.g. pain, nausea, and fatigue.^{7–10} To date, the majority of studies of symptom clusters have been guided by an empiricist paradigm, and have incorporated measures of symptoms and clusters using quantitative ratings of frequency, severity or bother and analytic strategies such as principal components analysis, cluster analysis, and multilevel classification analysis to group symptoms.^{15–17} Investigators have defined clusters of symptoms women experience by using statistical procedures such as factor analysis in order to group similar symptoms and cluster analysis or latent class analysis to group women having similar patterns of symptoms or occasions on which similar symptoms occur.^{1–4,6,8–18} This body of work indicates that common groups of co-occurring symptoms include hot flashes, sleep disruption, mood, cognitive, and pain symptoms. Some investigators have focused on whether these symptoms occur in a particular order, attempting to identify causal pathways among the symptoms, e.g. whether sleep symptoms precede hot flashes or hot flashes precede mood symptoms.^{19–20} Others have searched for correlates of these clusters of symptoms, such as endocrine correlates of clusters midlife women experience.²¹

Women’s experiences of the menopausal transition are highly personal and heterogeneous, as revealed in a recent postmodern feminist analysis of women’s narratives.²² Moreover, in this study women indicated that they experienced shame related to the public experience of symptoms such as hot flashes and linked these experiences to the stigmatizing of menopause as it is related to aging. The distress women experienced in relation to symptoms was

expressed often in silence about their symptoms in a context of prevailing social discourses about negative aspects of menopause and aging that discouraged their discussing their symptoms. Thus studying menopause symptom clusters using only traditional quantitative methods may fail to capture important aspects of women's experiences, including the meaning of their symptoms to them in the context of everyday life.

An alternative naturalistic paradigm incorporates approaches that invite people experiencing symptoms to impose their own definitions of symptom clusters, including asking them to identify, group, and prioritize symptom clusters they are experiencing and share their heuristics related to factors that they believe cause, exacerbate, and alleviate these symptoms/clusters.²³ In this context, heuristics refers to experience-based techniques for problem solving, learning, and discovery that offer solutions.²⁴ Women's ability to group their symptoms into clusters and name the clusters reflects their attempts to evaluate their symptoms in a holistic manner, as does the use of explanatory models to account for them.²⁵ Women's use of heuristics does not require an exhaustive search of all possible explanations for symptoms, thus speeding up the process of finding a satisfactory way of managing their symptoms by using mental shortcuts to ease the cognitive demand of determining what it is they are experiencing. For example, a woman may use heuristics to decide whether or not this cluster of symptoms represents a problem related to menopause, one that requires care from a professional, one that can be tolerated, or one that they can treat on their own. Heuristics women develop to account for their symptoms and approaches to managing them may rely on intuitive judgments (feels like ...), use of common sense, a rule (always seek health care for vaginal bleeding after menopause), an educated guess (suspect this is probably the flu), or cultural proscriptions (not good to have menopausal bleeding, bleeding unclean) and stereotyping (all women my age have ...).

Studies of symptom cluster heuristics explore personal, heterogeneous meanings and are typically motivated by interpretive methodologies that prompt researchers to engage participants in interviews eliciting narratives about their individual experiences.²³ These approaches are labor-intensive for both participants and researchers and expensive for funders to support. Moreover, they may be embarrassing for women who feel uncomfortable talking about their symptoms and challenging situations that occur when they experience symptoms in public. Using alternative data collection methods such as computer-administered questionnaires may create opportunities for women to express their symptoms and heuristics and also could enhance the ability to learn from larger and more heterogeneous populations of women than can be included in typical interpretive investigations.

A recent collaboration among menopause researchers and pediatric oncology nurse researchers led to development of an iPad app, the Computerized Symptom Capture Tool (C-SCAT), to study symptom clusters in adolescents and young adults with cancer.^{26,27} We recently evaluated the feasibility of the C-SCAT M, a modification of the C-SCAT app for studying midlife women's symptom clusters, with 30 women who experienced multiple symptoms they related to menopause.²⁸ Midlife women completed the C-SCAT M with little difficulty. Most (57%) indicated that using the app was very/extremely easy and most expressed a preference for using the iPad app rather than a paper-based version. In addition,

most (77%) indicated that the final diagrams of their symptom clusters were very/extremely accurate depictions. Initial evidence supported the feasibility, including usability and utility, of the C-SCAT M app for collecting data about symptom clusters experienced by midlife women.

Some of the potential benefits of using this innovative app with midlife women included the ability to collect data in ways that promoted women's privacy and did not expose them to embarrassing situations. Moreover, this approach would not require the expense of a researcher to conduct interviews, but could allow women to enter data in response to the app in real time, thus enhancing efficiency of data collection for studies of larger numbers of women than are typically recruited for qualitative research. In an unpublished pilot study we found that a paper-and-pencil based method of drawing symptom clusters and the relationship among symptoms was difficult and cumbersome for women. Using the iPad app allowed women to depict their symptoms, the relationships among them, and the clusters they formed with relative ease. The app also allowed them to modify their illustrations without having to erase a drawing or begin again.

Whether the use of the application with midlife women supports description of their heuristics remains to be evaluated. The analyses presented here, part of a larger feasibility study, focus on whether an iPad application, the Computerized Symptom Capture Tool - Menopause (C-SCAT M), could be used to study symptom clusters and women's heuristics in a sample of midlife women. The purpose of these analyses was to assess the use of the C-SCAT M app to elicit midlife women's heuristics about symptoms they were experiencing, including their ability to:

- group symptoms into a cluster;
- specify order of occurrence of symptoms;
- define or name the cluster in a way that was meaningful to them;
- articulate relationships, including causal relationships, among symptoms;
- attribute their symptoms to causes;
- identify exacerbating and ameliorating factors; and
- select high priority symptoms and clusters.

METHODS

Sample and Setting

Eligible participants were women recruited through advertisements posted on a university campus and in primary care and women's health clinics in the Seattle area and University of Washington campus. Women between the ages of 40 and 60 and who were experiencing symptoms they associated with menopause were screened for eligibility, including their ability to read and write English. Women who had conditions interfering with their ability to use a touch-screen computer, e.g. severe visual limitations, were excluded.

Forty-two women responded to advertisements, 8 declined participation, and 4 after enrollment was closed. Of the 30 women who began the study, all completed all parts of the study.

Study Measures

Computerized Symptom Capture Tool Menopause (C-SCAT M)—The C-SCAT M iPad app was modified for midlife women from the C-SCAT by computer programmers at Intermountain Healthcare's Homer Warner Center for Informatics Research (HWCIR).²⁹ The C-SCAT M includes 54 symptoms commonly reported by women during the menopausal transition and early postmenopause and studied in the Seattle Midlife Women's Health Study, a longitudinal study of a Seattle cohort as they experienced the menopausal transition.⁴ The C-SCAT M combines graphical images and free text responses in an innovative approach to explore the perspectives of participants about their symptoms and symptom clusters. C-SCAT-M presents the symptom menu and directs participants to drag and drop those symptoms experienced within the past 24 hours into a designated area on the iPad screen. Participants are prompted to draw connecting lines to indicate which symptoms are related and arrows to indicate causal relationships among symptoms and to draw boxes around clusters of symptoms that they perceived to be related, denoting the most important symptom in each cluster as well as the most bothersome cluster. Additionally, women were prompted to describe the temporal nature of the symptoms in the cluster/s and names they used for the clusters. Women were also asked to describe the cluster's cause, its effects on daily life, factors that exacerbated and relieved the clusters, and strategies they had found to manage the clusters. (See Figure 1)

The C-SCAT-M generates a final graphical image that includes individual symptoms, relationships between symptoms, symptom clusters, and key symptoms within clusters. Women are asked whether the graphical image accurately represents their experience. (See Figure 2)

Demographic and Clinical Data—Demographic data were obtained from participants to describe the study sample. These included their current age, educational attainment, menstrual/menopause status, current computer use, and experience using an iPad.

Procedures

Recruitment and Enrollment—Following IRB approval, midlife women between 40 and 60 years of age and who self-reported experiencing symptoms they believed were related to menopause were recruited from advertisements in public places on a university campus and in primary care clinics. Each enrolled participant received a \$20 gift card as a token of appreciation.

Data Collection—Participants completed the C-SCAT-M on a dedicated study iPad in a quiet private location in either an investigator's office or in another area of the university, e.g. conference room in the library. Following completion of the C-SCAT-M, participants also completed an acceptability questionnaire, results of which are reported elsewhere.²⁸ A research team member remained available during participant sessions to answer questions

and to record comments women made as they were encouraged to think aloud about their experience using the app. Comments women made while thinking aloud were collected to inform revisions in the app, but were not analyzed as qualitative data related to women's heuristics.

Data Management and Analysis

As women completed the C-SCAT M, graphic and text data generated by participants were encrypted and wirelessly transmitted securely to a password-protected Amazon Simple Storage Service (S³) account. Amazon S³ is a secure, distributed network for storing and retrieving data that is compliant with Health Insurance Portability and Accountability Act (HIPAA) standards.³⁰ Data from each participant included screen shot images of each stage of the app's completion and an Excel worksheet containing free text responses. Data were downloaded from the Amazon Web Services S³ site and stored on an encrypted, password-protected computer in preparation for data analysis. SPSS version 21 was used to create data files for statistical analysis. Free text data from the C-SCAT M were analyzed using simple descriptive statistics to characterize the numbers of symptoms and symptom clusters. Symptom relationships were identified by visual inspection of the final symptom diagrams and review of Excel worksheets. For causal relationships, the symptom caused was identified as the symptom at the end of the arrowhead and the symptom of origin as the symptom at the end of an arrow without an arrowhead. Relationships included any bivariate connection between two symptoms regardless of whether the relationship was depicted as a causal relationship or not. Visual inspection of the diagrams elicited the priority clusters and priority symptoms within the clusters as indicated by a ribbon icon they placed on the priority clusters and symptoms.

Conventional content analysis was used to identify themes in the text data related to the names women assigned to the clusters, attributions of the symptom clusters to causes, factors exacerbating and alleviating the clusters, and women's approaches to management of their symptom clusters.³¹

Results

Participants ranged in age from 40 to 60 years, and two thirds were 50 years and older. A well-educated sample, 77% had completed 4 years of college or graduate school. The majority was experiencing the menopausal transition or postmenopause, either skipping periods (13%) or having had no menses for over a year (43%). Only one reported having regular periods during the past year.

Symptoms and Relationships

Symptoms Reported—Women were able to select symptoms they had experienced in the past 24 hours using a drag and drop method on the touch screen without difficulty. They reported an average of 11 symptoms (median = 11, range 1 to 22). Sixteen percent reported from 1–5 symptoms, 33% reported 6–10, 36% reported 11–15, 3% reported 16–20, and 10% reported over 20 symptoms. A summary of the frequency with which women identified specific symptoms is given in Table 1. The five most frequently reported symptoms

included hot flashes/sudden warmth (57%), waking up during the night (53%), early morning awakening (50%), night sweats (47%), and fatigue (43%). The most bothersome symptoms women reported were hot flashes followed by waking up at night and fatigue. They rated their most important symptoms as hot flashes, waking up at night and fatigue.

Relationships among Symptoms—Women identified relationships between individual symptoms by drawing lines connecting them. They indicated 323 relationships between symptoms. As seen in Table 2, the relationships women reported most commonly were between hot flashes and night sweats, depressed mood, cold sweats, difficulty falling asleep, early morning awakening, waking up during the night, anxiety, difficulty concentrating, fatigue, tiredness, joint or muscle pain, and skin breakout/acne. Women related waking up during the night to fatigue, tiredness, early morning awakening, anxiety, hot flashes/sudden warmth, night sweats, tension, and difficulty falling asleep. They linked early morning awakening to fatigue/tiredness, sense of urgency before losing urine, waking up during the night, forgetfulness, and increased sleeping. Women associated night sweats with waking up during the night, early morning awakening, cold sweats, hot flashes/sudden warmth. They related fatigue to a decreased desire to talk/move, difficulty making decisions, difficulty falling asleep, food cravings, difficulty concentrating, backache, irritability, depressed/sad or blue, early morning awakening, sensation of weight gain, and impatience.

Causal Relationships Between Symptoms—In addition to identifying relationships among symptoms women were also asked to indicate whether any of the symptoms caused any others by using a unidirectional arrow between two symptoms. Women also were able to identify over 150 unique causal paths between symptoms. As seen in Table 3, women reported most often causal relationships between hot flashes and other vasomotor symptoms (cold sweats, night sweats) as well as other symptoms, such as sleep, mood, cognitive, and pain symptoms. Women indicated that their hot flashes caused several varieties of symptoms, with the largest number of women reporting that hot flashes caused sleep disruption. Also women reported that hot flashes caused mood, cognitive, and pain symptoms as well as urinary urgency. Women indicated that their hot flashes caused night sweats and that night sweats caused cold sweats. One woman reported a cyclic pattern in which hot flashes caused night sweats, which caused cold sweats, which caused more hot flashes. (See Figure 3 for illustration of the causal paths identified between hot flashes and other symptoms)

Time-ordering of symptoms—Some women were able to describe in detail the time ordering of their symptoms and others indicated that their symptoms did not occur in any particular order. For example, one woman said: “I wake up due to being overheated and sweating, so heat comes first.” Another woman commented “1) hot flash, 2) night sweat, cold sweat, difficult falling back to sleep, then early wakening and tired next day.” Another commented that “sleeplessness starts cycle” and another commented that symptoms “always start with depressed, difficulty concentrating, forgetfulness.” Others indicated “no particular order”.

Symptom Cluster Heuristics

Heuristics women used to evaluate their symptoms were reflected in their identifying clusters of symptoms, naming the clusters, assigning priority to the clusters, revealing explanatory models of causes of their symptom clusters, and identifying factors that ameliorated or exacerbated them.

Identifying clusters—Women identified clusters of symptoms they experienced by drawing a box around the individual clusters as prompted by the app. Women reported from 1 to 4 clusters, with 27% (n=9) reporting 1 cluster, 37% reporting 2 clusters (n=12), 17% (n=5) reporting 3 clusters, and 3% (n=1) reporting 4 clusters. Aside from one woman who indicated she had only a single symptom, all participants were able to assign at least some of their symptoms to a cluster. Many women (63%) reported combinations of clusters and single symptoms they did not assign to a cluster. The number of symptoms per cluster ranged from 2 to 18.

Naming the cluster—With one exception, each participant was able to “name” her clusters. Some of the names reflected symptoms included in the clusters, for example, “gi problems,” “poor quality sleep,” “hot flashes,” and “urgency.” Other names reflected women’s evaluations of their experience of the cluster, e.g. “unpleasant middle-aged woman group” referring to sexual problems, “my pain in the ass” – mentally generated issues that included confusion, forgetfulness, tearfulness, feeling impatient, joint or muscle pain, lonely, headache, anger, difficulty concentrating, irritable, nervous, panic feelings. Another cluster was named “last stop” reflecting feeling overwhelmed; and “hamster wheel” including symptoms of fatigue, early morning awakening, waking up during the night, cold sweats, night sweats, and difficulty falling asleep. Others reflected emotional distress exemplified by “feel like I am crazy”, “pure craziness”, “out of control”. Some names implied a mechanism, e.g. “sympathetic nervous system”, “PMS”, “estrogen exodus”. Still other names referred to the time of occurrence of the cluster: “night problem,” “blue mornings,” “dark hours.” These clusters each included sleep symptoms as well as emotional symptoms. Other names indicated the intensity of the symptoms in the cluster: one woman named her three clusters “slight”, “stress”, and “terror.” Some names referred explicitly to age and aging, e.g. “51” and “aging”. Some cluster names women used referred to social and family phenomena, e.g. “missing my daughter”, “missing home and family.” The names women assigned to their clusters suggest the types of heuristics they have about them. (See Table 4)

Women were also asked about the effect of each symptom cluster on their daily activities. Most women complained of emotional effects linked to their symptom clusters, such as being irritable, increasing levels of frustration and stress, and feeling depressed. Some women felt tired due to waking up during the night or having hot flashes. Their symptom clusters also affected their physical condition, such as urinary frequency causing them to look for or run to the bathroom, being slowed down, or having sexual problems.

Assigning priority to clusters—When asked to identify their most bothersome symptom cluster, each woman was able to indicate which cluster they considered to be most

bothersome by placing a ribbon icon on that symptom cluster. Seven of the 29 women reporting clusters selected a priority cluster related to sleep problems, with an additional 2 women indicating their priority cluster involved fatigue or tiredness. Seven women also selected clusters that reflected emotional symptoms or stress. Five women indicated a priority cluster involving hot flashes. Two women chose a cluster involving urine loss or frequency as their priority cluster.

Women also identified a priority symptom in each cluster by placing a ribbon icon on that symptom, indicating which was most important. These were specific to the type of symptoms included in the cluster. Symptoms women considered most important and the number reporting the symptom included: fatigue (4), waking up during the night (4), hot flashes (4), anxiety (3) night sweats (2), early morning awakening (2). Priority symptoms reported by one women for each included: depressed, difficulty concentrating, difficulty falling asleep, anger, decreased sexual desire, headache, increased sleeping, urinary urgency, skin breakout and forgetfulness.

Making causal attributions—Women were also able to identify what they believed caused their symptom clusters. Among the causal attributions they made were: menopause, including the physiological hormonal changes occurring during the perimenopause; life demands, including juggling multiple responsibilities such as work, relationships with children and others, economic insecurity; stress and worry; other symptoms, e.g. sweats causing sleep disruption; and aging. Despite the administration of these questions via a touch screen, many women elaborated on their heuristics in sentences. One woman related her attributions about sleep symptoms: “I am tired but can’t sleep, have difficulty falling back to sleep, particularly with night sweats ... always remain awake ... when sleep interrupted past 3 am.” Another said, “I don’t feel like my life is how I want it to be so that irritates me and makes me want to eat more, especially sugar.” Yet another wrote, “whenever I think of something sad or irritating it makes me have a hot flash.”

Identifying exacerbating and ameliorating factors—Women also responded to the questions: “What do you think makes it (the cluster) better? What do you think makes it worse?” and “Have you tried anything that makes it better? Makes it worse?” In response to these questions women offered many strategies for managing their symptoms, including use of over the counter medications; sleeping, resting and taking vacations; limiting eating; reading a book, going out, meeting someone, doing something enjoyable; using cotton sheets and white noise for sleep; losing weight.

Strategies that resulted in improvement in symptom clusters included over the counter sleep medications; resting, relaxing, and de-stressing; making dietary changes such as cutting back on sugar intake, drinking more water, using yogurt with bacterial cultures; exercising; doing something pleasant, e.g. reading, going to the beach; having a glass of wine or reducing alcohol intake; breathing and waiting it (hot flash) out; using herbal therapy for hot flashes; watching sexually arousing movies; and having acupuncture. Factors that made symptom clusters worse included: eating more sugar, eating too close to bedtime; being stressed; trying to “think my way out of it”, focusing on one particular problem; gaining weight; being isolated; being tired from not sleeping; and drinking water too close to bedtime. In

most instances women noted that not using some of the strategies that ameliorated the symptom clusters exacerbated them.

Discussion

This study of women's symptom clusters and heuristics using an iPad app, the C-SCAT M, revealed that women were able to report their symptoms, group them into clusters, specify the order of occurrence, name the cluster in ways that had meaning for them, and articulate relationships, including causal relationships, among the symptoms. Women also could identify a cluster they rated as most important and a symptom within that cluster they rated as most bothersome. In addition, women were able to articulate their causal attributions and account for what exacerbated or relieved the clusters of symptoms they experienced.

Women's responses to the iPad app revealed the heuristics they used in managing their symptoms. Their heuristics included those accounting for the causal relationships among symptoms and time-ordering of their occurrence. In addition women were able to group symptoms that co-occurred and assign names to the clusters. The clustering and naming of the symptoms suggest that the heuristics women use for evaluating their symptoms included consideration of distress they generated, mechanisms responsible for them, attributions to aging and menopause, and the impact on their lives. Women's causal attributions included menopause, aging, life demands and stress. Their ability to evaluate factors that exacerbated and alleviated their symptoms was linked to attempts at self care. Taken together, these findings indicate that women generated explanatory models, as described by Chrisman and Kleinman,²⁵ and had formulated narratives that accounted for what the cluster represented, reflected in the names they assigned them. Names reflected causes, meanings of the clusters, and mechanisms, similar to those commonly used in medical diagnoses in some cases.

Framing the symptoms was indicated by the approaches women used to group the symptoms in clusters and to name the cluster with words or phrases suggesting the meaning of the cluster to them. Some of the names reflected women's beliefs about their symptoms ("unpleasant middle-aged women group") or appraisals of their symptom experiences ("last stop" or "terror"). Hunter found that women's approaches to detection and attribution of symptoms were influenced by body focus, mood, and stress. In turn, their cognitive appraisals of symptoms, such as hot flashes, were influenced by beliefs about the symptoms (hot flashes) and their mood. These appraisals, in turn, prompted behavioral responses such as help-seeking.³² Naming the symptom clusters may allow women to communicate their beliefs about their symptoms or their appraisals. Naming the symptoms also hinted at the attributions of the symptoms to causes such as "estrogen exodus". The naming process as well as women's response to questions about their causal attributions thus may play an important role in understanding their help-seeking efforts. Of interest is that Hunter and colleagues have developed and tested interventions that target beliefs about symptoms as a key element in their treatment model. Indeed, changing cognitive appraisals, but not mood, was responsible for treatment effects.³³

Our prior pilot study with paper-and-pencil methods revealed that for women who experienced multiple symptoms, that method had several limitations. Among the most

important limitations was that women were unable to draw the relationships among symptoms and group them into clusters without having to redraw their models several times. The complexity of the relationships among symptoms, as well as between clusters, suggests that usability of the C-SCAT M app for clinical care should be investigated. Indeed, some commented spontaneously that their diagrams, which they rated as accurately representing their symptoms, would be helpful to take to their appointments with a health care provider to facilitate explaining their symptom experiences. Indeed, modification of the iPad app to generate a report of women's experiences could be useful in helping them have optimal conversations with their health care providers.

Although women with the most complex symptom relationships and clusters may have an overwhelming amount of information to share with a health care provider, it is important to note that women were able to prioritize the clusters that were most bothersome and most important to them. In addition, they were able to express their heuristics, including causal attributions and factors that exacerbated or relieved their symptom clusters. Generation of a report that could be shared with health care providers could provide a starting point for health care visits in which women would be supported to articulate clearly the symptom clusters of greatest importance to them and to negotiate the use of the appointment in ways that helped meet their personal priorities for care. Indeed, such an approach may be useful to health care providers seeking to understand the complexity of women's symptoms, their notions about causality, and the self care and treatment options women had evaluated, all within a limited period of time. In addition, introduction of such a report in practice settings may enhance women's satisfaction with the care they receive as it could cue providers to address what matters most to patients. Health care providers may be aided by having a report summarizing women's experiences that they could review at the beginning of a visit to use as a guide for further assessment and consideration of possible treatment options.

Negotiating perspectives about symptoms and women's heuristics could also introduce challenges in already time-limited and complex health care situations. For this reason, exploration of the utility of an app such as the C-SCAT M should be pursued from the perspectives of health care providers to determine whether such an app and the type of report generated from it would be acceptable to them and whether the app and related reports would be usable and useful in clinical settings. Nonetheless, understanding the heuristics women have for dealing with their symptoms could contribute an important foundation for health promotion and maintenance in both primary care and specialty settings. As the app is tested in the real context of health care delivery systems, assessment of the priorities of both women patients and health care providers, approaches to intervention related to heuristics used by both (women's causal models and those of health care providers), and approaches to resolving conflicting priorities and mental models prompt future research.

Limitations of this study include the modest sample size, although the inclusion of 30 women in a pilot study assessing the feasibility of using an app such as that tested here would be considered adequate.³⁵ Moreover, naturalistic/interpretive studies would use the criterion of saturation to determine sample size and it would not be unusual for inclusion of fewer than 30 participants to be considered adequate. Nonetheless, further research is

needed with a more heterogeneous population of women given the well-educated participants in this study.

Conclusions

In summary, the C-SCAT M provided women an opportunity to elaborate their heuristics related to symptoms and symptom clusters they experience around the time of menopause. Next steps in this research should include modification of the C-SCAT M app and evaluation of its use in health care settings.

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Figure 1a.

Groups and Group Details?

Draw a rectangle around symptoms that occur together as a group.

Drag on the sides of each rectangle as needed to change its size.

Move the symptom square as needed to fit them in the rectangles.

After you have drawn rectangles around the symptom groups "Double Tap" on each rectangle to answer questions about that group.

"Press and Hold" to delete a group.

Group Details

Symptoms: Early morning awakening, Hot flashes/sudden warmth, Impatient, Irritable

What name would you give to this symptom group?

What do you think is the cause of this symptom group?

What effect does this symptom group have on your daily activities?

Cancel Save

C-SCAT-M - Participant #999

Figure 1b.

Priority Group Details

How long have you been experiencing this symptom group? When did it start?

Do you experience all of the symptoms in this group at the same time?

If you don't experience them all at the same time, do you usually experience them in an order, e.g. does one happen first, then another?

Do you think that any of these symptoms causes another/others? Please describe.

What do you think makes it better?

What do you think makes it worse?

Have you tried anything that made it better? What was that?

Cancel Save

Figure 1.

Screens eliciting data on Women's Symptom Cluster Heuristics. Figure 1a includes questions about name, causes, and consequences of the symptom cluster. Figure 1b includes questions about the time order of the symptoms in the cluster, the factors exacerbating and ameliorating the cluster, and management strategies the woman has tried.

Figure 2a.

Figure 2b.

Figure 2. Illustration of Symptom Cluster Diagram created in C-SCAT M

Figure 2a includes two symptom clusters and one symptom not related to the clusters. The clusters are named “hot flash group” and “mental challenges”. The hot flash cluster is rated as the most bothersome (blue ribbon) and the hot flash symptom as the most important (red ribbon). Forgetfulness is named as the most important symptom in the mental challenges cluster. Waking up during the night is not related to other symptoms or clusters. Five causal paths are delineated by arrows between symptoms.

Figure 2b includes four clusters labeled as “hot flash anxiety”, “night sweats”, “withdrawal”, and “food”. The most bothersome cluster identified as hot flash anxiety (blue ribbon) and the most important symptom in that cluster is hot flashes (red ribbon). Forgetfulness, hot

flashes and anxiety are included in this cluster. Hot flashes cause difficulty concentrating (single arrowhead) and both hot flashes and anxiety have reciprocal relationships to out of control feelings (see arrows with two arrowheads). Four symptoms are not included in a cluster in this diagram: rapid mood changes, impatient, cold sweats and backache. In the night sweats cluster, night sweats cause early morning awakening and night sweats are the most important symptom. The withdrawal cluster includes out of control feelings (most important), decreased desire to talk or move, difficulty concentrating and difficulty making decisions. The food cluster includes fatigue/tiredness (most important), sensation of weight gain and food cravings.

Figure 3.
Women's Causal Paths from Hot Flashes to Other Symptoms

Table 1

Symptoms Reported in Order of Frequency: Frequency and Percent of Total Number Reporting

No	Symptom	Frequency	Percent
1.	Hot flashes/sudden warmth	17	56.7
2.	Waking up during the night	16	53.3
3.	Early morning awakening	15	50
4.	Night sweats	14	46.7
5.	Fatigue, tiredness	13	43.3
6.	Backache	12	40
7.	Difficulty falling asleep	11	36.7
8.	Forgetfulness	11	36.7
9.	Impatient	11	36.7
10.	Irritable	11	36.7
11.	Joint or muscle pain	11	36.7
12.	Anxiety	10	33.3
13.	Bloat	10	33.3
14.	Difficulty concentrating	10	33.3
15.	Headache	8	26.7
16.	Sensation of weight gain	8	26.7
17.	Sense of urgency before losing your urine	8	26.7
18.	Difficulty making decisions	7	23.3
19.	Increased food intake	7	23.3
20.	Losing urine when you cough or sneeze	7	23.3
21.	Depressed	6	20
22.	Out of control feelings/overwhelmed	6	20
23.	Tension	6	20
24.	Anger	5	16.7
25.	Cold sweat	5	16.7
26.	Confusion	5	16.7
27.	Nervous/jittery	5	16.7
28.	Tearfulness/crying spells	5	16.7
29.	Vaginal dryness	5	16.7
30.	Abdominal pain	4	13.3
31.	Breast tenderness	4	13.3
32.	Constipation	4	13.3
33.	Decreased desire to talk/move	4	13.3
34.	Hopeless feelings	4	13.3
35.	Lonely	4	13.3
36.	Panic feelings	4	13.3
37.	Rapid mood changes	4	13.3

No	Symptom	Frequency	Percent
38.	Desire to be alone	3	10
39.	Guilt feelings	3	10
40.	Heart pounding	3	10
41.	Hostility	3	10
42.	Nausea	3	10
43.	Skin breakout/acne	3	10
44.	Swelling of hands or feet	3	10
45.	Decreased sexual desire	2	6.7
46.	Dizziness	2	6.7
47.	Cramps (uterine/pelvic)	1	3.3
48.	Diarrhea	1	3.3
49.	Food cravings	1	3.3
50.	Increased cold sensitivity	1	3.3
51.	Increased sleeping	1	3.3
52.	Vaginal itchiness	1	3.3
53.	Vaginal pain with intercourse	1	3.3
54.	Decreased food intake	0	0

Table 2

Relations between Symptoms: Frequency

Origin Symptom (5 most frequently reported symptoms) (n=women reporting)	Related symptoms in order of frequency (n=women reporting relationship)			
Hot flashes (n=17 women reporting)	Night sweats (n=4)	Depressed mood (n=2)	Cold sweat (n=2)	Difficulty falling asleep (n=2)
	Early morning awakening (n=2)	Waking up during the night (n=2)	Anxiety (n=1)	Difficulty concentrating (n=1)
	Fatigue, tiredness (n=1)	Joint or muscle pain (n=1)	Skin breakout/acne (n=1)	
Waking up during the night (n=16)	Fatigue, tiredness (n=4)	Early morning awakening (n=1)	Anxiety (n=1)	Hot flashes/sudden warmth (n=1)
	Night sweats (n=1)	Tension (n=1)	Difficulty falling asleep (n=1)	
Early morning awakening (n=15)	Fatigue, tiredness (n=4)	Sense of urgency before losing your urine (n=2)	Waking up during the night (n=1)	Forgetfulness (n=1)
	Increased sleeping (n=1)			
Night sweats (n=14)	Waking up during the night (n=3)	Early morning awakening (n=3)	Cold sweats (n=2)	Hot flashes/sudden warmth (n=1)
Fatigue (n=13)	Decreased desire to talk/move (n=2)	Early morning awakening (n=2)	Difficulty falling asleep (n=1)	Food cravings (n=1)
	Difficulty concentrating (n=1)	Backache (n=1)	Irritable (n=1)	Depressed/sad or blue (n=1)
	Difficulty making decisions (n=1)	Sensation of weight gain (n=1)	Impatient (n=1)	

Table 3
Causal Paths Between Vasomotor Symptoms and Other Symptoms (n=number reporting relationship)

Causal Symptom	Effect Symptoms	Sleep Symptoms	Mood symptoms	Cognitive Symptoms	Pain Symptoms	Other
	Vasomotor Symptoms					
Hot flashes	Night sweats (4), Cold sweats (1)	Night-time awakening (3), difficulty falling asleep (2), early am awakening (2)	Out of control (1), anxiety (1),	Difficulty concentrating (2)	Joint/muscle pain (1)	Urgency (1)
Night sweats		Awakening at night (3), early am awakening, (3), increased sleeping (1)				
Cold sweats		Night-time awakening (1)				

Table 4

Women's Names for Symptom Clusters

Conventions for Naming Symptom Clusters	Examples of Symptom Cluster Names
Symptoms in the cluster	GI problems Poor quality sleep
Evaluations of their experience	Unpleasant middle aged woman group Last stop
Emotional distress	Feel like I am crazy Out of control
Mechanism responsible for symptom cluster	PMS Estrogen exodus Sympathetic nervous system
Time of occurrence	Night problems Blue morning
Intensity of symptom cluster	Slight Stress terror
Age and aging	51 aging
Social and family phenomena	Missing my daughter Missing home and family