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Feature Article

# Complementary/alternative therapies use in older women with arthritis: Information sources and factors influencing dialog with health care providers

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ABSTRACT

The purpose of this study was to describe the information sources older women with arthritis use to make decisions about complementary/alternative therapies (C/AT), and factors that influence C/AT dialog with their HCP. The purposive sample included 50 community-dwelling older women (mean age = 77.8, SD = 7.6, range 66–101) who were using C/AT for arthritis management. Eight focus groups were conducted. Qualitative data were analyzed using both manual and computer-based (Atlas.ti) methods. Participants used a variety of C/AT for arthritis management. Most did not seek C/AT information from their health care provider (HCP) but primarily relied on family and friends as resources. Common themes that influenced C/AT dialog included collaborative patient relationship with HCP, HCP unsupportive attitudes toward C/AT and lack of C/AT knowledge, and time-limited clinic visits. Clinical implications include fostering shared decision making clinical relationships, increasing HCP knowledge about C/AT, initiating C/AT dialog and offering credible C/AT information sources.



## Introduction & literature review

Arthritis negatively impacts 52.5 million people in the United States, with the National Center for Chronic Disease Prevention and Health Promotion estimating that this number will reach 67 million people by 2030.[1] The chronic intermittent and often debilitating pain of many types of arthritis typically impacts patients in a myriad of ways including the ability to complete activities of daily living, mobility, sleep, and levels of social engagement.[2] Current reports indicate that 50% of the population over the age of 65 are affected by some form of arthritis with the prevalence in women significantly higher than that of men,[3] making it a widespread issue for elderly women.

Elderly patients with arthritis often turn to complementary/alternative therapies (C/AT) (e.g. natural products including supplements, mind/body practices) because they were dissatisfied with symptom management, including inadequate and unreliable pain control, negative side effects of medications, and the desire to avoid invasive procedures.[4–7] In fact, arthritis patients are one of the highest user groups of C/AT, including oral supplements, with as many of 90% using some form of C/AT to manage their symptoms.[4,5] These patients often perceive C/AT to be safe, effective, and useful management tools[5,8] However, while many C/AT, such as acupuncture,[9] tai chi,[10] and massage[11] are safe and effective arthritis management tools, some C/AT like glucosamine and chondroitin do have adverse effects and potential risk of interactions with conventional arthritis treatments.[12–15] Because of age-related changes in pharmacokinetics/pharmacodynamics and use of prescription drugs, older adults are at higher risk than people in other age groups for potential adverse interactions involving prescription medication and herbs or high-dose supplements.[16,17] Given the high rate of older people who use C/AT to manage their arthritis, it is important for health care providers (HCP) to know about patient C/AT use and be in dialog with their patients about C/AT use in order to prevent risk, promote safety, and better understand the role of C/AT in arthritis management.

A review of both quantitative and qualitative studies indicates that HCP are often not aware of and/or significantly underestimate patient C/AT use,[18] both because HCP don't ask patients about C/AT use and because patients don't tell their HCP about their use.[19,20] If patients and HCP are not discussing C/AT use, it begs the questions, where are patients getting their information about C/AT? Do older arthritis patients use credible or evidence-based resources for C/AT

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information? The purpose of this study was to describe the information sources older women with arthritis use to make decisions about C/AT and factors that influence C/AT dialog between older arthritis patients and their HCP. In this study, the term C/AT was used to define a group of health treatments or remedies that are used outside of, or in combination with conventional medicine.

## Design and methods

A qualitative study using a purposive sample of community-dwelling older women with arthritis was conducted. Eight semi-structured focus group sessions (4–8 per group) were held at a variety of locations.

### *Sampling and recruitment*

Participants were recruited from Minneapolis/St. Paul, Minnesota and surrounding suburban and rural communities within a 100-mile radius via flyers posted at various community locations such as senior centers, health food stores, senior high-rise apartment buildings, and faith communities. Researchers also met with activity directors from senior community centers and then either conducted a recruitment presentation at the center's ongoing activities and/or asked the directors to give potential participants researcher contact information. Approximately 65 people inquired about the study. Fifty-five met the initial screening criteria and fifty agreed to participate in the study and were available at the time of the focus groups. Inclusion criteria included women who were: 1) aged 65 years or older; 2) community dwelling (non-institutionalized individuals who have access to C/AT and are able to make health care choices), 3) had been diagnosed with arthritis for at least one year; and 4) were using at least one form of C/AT to manage their arthritis symptoms.

### *Data collection procedures*

A reminder call was made to all participants one day prior to the focus group meeting to verify the time and place. Participants were instructed to reflect on their experience of using C/AT to manage arthritis. Researchers used The Health Belief Model,[21] the literature on C/AT utilization[4–8] and the research team's knowledge of older women's experiences of arthritis to develop the focus group questions. Questions were piloted in a previous qualitative study that explored the use of C/AT in older women with arthritis.[5] Prior research indicated older women are more familiar with the term "alternative medicine" than "complementary/alternative therapy," thus the term "alternative medicine" was used in the focus group questions.[5] Focus group questions included the following: "*Where do you get information about alternative medicine?*" "*Do you talk to your health care providers about alternative medicine?*" "*Do you consult research or evidence-based literature when you are gathering information about alternative medicine*?" Because qualitative research is an interactive process, focus group questions were modified slightly after each focus group with some changes in emphasis on the questions being introduced in order to explore issues that surfaced in prior focus groups.[22] A handout with commonly used C/AT words was distributed to participants during the sessions to provide common vocabulary among participants.

Each focus group lasted approximately one to one and a half hours. An official welcome and a brief introduction of the study were offered at the beginning of each meeting. This study was approved by the St. Catherine University Institutional Review Board and each participant signed a consent form before the focus group discussion began. The moderators used the focus group questions to initiate open-ended discussions on issues related to the older women using C/AT to manage arthritis. At the end of the group each participant received a $25 gift certificate to a local grocery store. The research assistant transcribed audio-taped sessions verbatim. The transcripts were checked by two researchers for accuracy against the tapes.

Researchers collected and analyzed the following forms of data to support data triangulation[22]: 1) transcripts from the focus groups, 2) extensive field notes taken by the researchers at each focus group including participant characteristics, phrases or words used, participant enthusiasm, body language, and the overall mood of the discussion, 3) notes recorded by the moderator on a large flip chart during the focus group sessions, and 4) researchers' summaries of each focus group which included both compared notes and shared observations were collected via a short survey at the conclusion of each focus group.

### *Data analysis*

Data analysis proceeded in two ways. First, the researchers employed an inductive analytic process suggested in the literature.[23] The interdisciplinary research team (nursing, occupational therapy, psychology, holistic health) first independently read all transcripts reflecting the entire description of the experience to get a sense of the whole and identified possible codes. After discussing the codes, the research team collapsed codes into common categories within and across groups in response to the key questions. Inter-rater reliability was assessed by meeting and comparing the data each researcher had initially coded. Through dialog about contextual factors, personal interpretations, and biases, researchers reached consensus on which data to include and exclude. Key words and phrases were grouped into a chart of the overarching research questions. Next, the research team reflected on the words, phrases, and blocks of text within each theme, allowing for interpretation, comparison, and additional emergence of themes.

After the manual data analysis was completed, the researchers used Atlas.ti software, a computerized data analysis software program designed for qualitative inquiry. The purpose for using Atlas.ti in this study was to allow researchers to cross-check their initial findings and allow richer understandings of participants' experiences. After merging all redundant codes (e.g. "fish oil" and "omega-3s"), links were created to identify their conceptual relationships (e.g. codes that supported, built upon, or contradicted each other). Electronic "memos" within Atlas.ti were used to indicate interpretations, relation to theory, and topics for further inquiry.

In qualitative research, validity is based on the richness of the data and the analytical capabilities of the researchers.[22] In this study, the interdisciplinary backgrounds of the researchers helped them to view the data from multiple perspectives, allowing rich dialog about the data. Data collected from multiple sources (transcripts, field notes, flip chart recordings, researcher summaries) and geographical locations (urban, suburban, rural) enhanced triangulation of the data. The process of electronic coding, linking ideas, and use of memos to communicate abstract ideas provided a more explicit "audit trail" to understand how the researchers' interpretations came about. The interdisciplinary backgrounds of the researchers, data triangulation, and the multi-step process of coding, strengthened the data analysis process.

## Results

Participants were 50 women over the age of 65 (mean = 77.8, range 66–101, SD = 7.55), primarily Caucasian (Caucasian = 90%, African American = 10%), had some college education (mean = 14.13 years, range 8–22, SD = 2.61), were widowed