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**Formal and informal health care behaviours of women with chronic illness: A cross-sectional analysis of 1,925 women**

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**Formal and informal health care behaviours of women with chronic illness: A cross-sectional analysis of 1,925 women**

**Running title:** Use of health care by women with chronic illness

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This research was completed using data collected through the 45 and Up Study ([www.saxinstitute.org.au](http://www.saxinstitute.org.au)). The 45 and Up Study is managed by the Sax Institute in collaboration with major partner Cancer Council NSW; and partners: the National Heart Foundation of Australia (NSW Division); NSW Ministry of Health; NSW Government Family & Community Services – Ageing, Carers and the Disability Council NSW; and the Australian Red Cross Blood Service. We thank the many thousands of people participating in the 45 and Up Study, and especially those women participating in the present sub-study.

# Formal and informal health care behaviours of women with chronic illness: A cross-sectional analysis of 1,925 women

## Abstract

**Aim:** To describe the health care behaviours of Australian women (45 years and over) diagnosed with a chronic illness.

**Methods:** This is a cross-sectional sub-study of the 45 and Up Study—the largest study of healthy ageing conducted in the Southern Hemisphere—including 1,932 Australian women (45 years and older) with a self-reported diagnosis of either depression, asthma, diabetes, osteoarthritis, or osteoporosis. Questionnaires were posted to eligible participants between September and December 2016 and included self-reported use of formal and informal health services and health care behaviours, and health practitioner recommendations and monitoring of informal care. Descriptive statistics were used to describe the sample characteristics and chi-square tests assessed associations between variables.

**Results:** The average age of participants was 69. We found that 53.7% of the women used informal health care products or practices for their chronic illness (e.g. exercise, nutritional supplements). These women were significantly ( $p < 0.001$ ) more likely to consult with all types of health practitioners, compared to women not using informal health care. Physical activity and nutritional supplements were the most commonly recommended product or practice by all health care practitioners. However, informal health care behaviours were not regularly recommended or monitored by health practitioners.

**Conclusions:** Women use a range of informal products and practices to manage chronic illness, but many fail to communicate with their health practitioners about such use. Future research should consider how to encourage better communication between health practitioners and patients related to informal health care for chronic illness to help ensure safe, effective, coordinated patient management.

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**Key words:** Women’s Health; Chronic Illness; Health Services; Self Care; Health Behaviour;  
Delivery of Health Care

**What is already known about this topic?**

- Chronic illness produces significant personal and societal burden and is a leading cause of death worldwide.
- The likelihood of developing comorbid chronic illness increases with age, and women are more likely to experience specific types of chronic illness compared to men.
- Informal health care use by women with chronic illness involves self-care maintenance behaviours that may not always be disclosed to their medical provider.

**What does this article add?**

- The first study to investigate formal and informal health seeking of Australian women aged 45 years and older diagnosed with one of five chronic illnesses.
- Women used a range of informal health products and practices to manage chronic illness.
- Many women did not communicate with health care providers about their use of informal health care products and practices, and the majority of these behaviours were not monitored by health practitioners.

## Introduction

Chronic illness produces significant personal and societal burden [1], and is a leading cause of death worldwide, killing more than 40 million people each year [1]. In Australia, more than 50% of the population have at least one chronic illness, and 23% report two or more chronic illnesses [2]. The likelihood of developing comorbid chronic illness increases with age [3], and women are more likely to report a diagnosis of either asthma, arthritis, osteoporosis [3], or depressive disorder [4, 5].

In addition to utilising conventional practitioner-led treatments and practices, many people seek informal health care (constituting both self-care/prescribed practices and products that can involve minimal or no health practitioner involvement [e.g. meditation, herbal medicines and nutritional supplements]). Informal health care also includes consultation with, and treatments administered by, a range of health practitioners not traditionally associated with the medical curriculum or profession (e.g. acupuncturist, chiropractor and naturopath) to help manage and live with their chronic illness, prevent future illness and maintain wellbeing [6, 7]. What constitutes informal health care varies between countries as each has a unique health care system and regulatory requirements. In this study informal health care is defined within the context of the Australian health care system, which may not reflect that of other countries.

The use of formal and informal health care by women with chronic illness involves self-care maintenance behaviours that aim to improve and preserve health [8]. Health care practitioners increasingly recognise that supporting patient self-care behaviours, such as physical activity, is crucial to managing chronic illness [9, 10]. In addition, the National Strategic Framework for Chronic Conditions (NSFCC) developed by the Australian government emphasises effective self-care as one essential component of preventing and managing chronic illness [2]. However, there are varying levels of evidence for informal health products and practices, such as herbal medicine and yoga [11-13], and many informal treatments are not included in clinical guidelines for chronic disease management [14, 15].

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Women with chronic illness are more likely, compared to men with chronic illness, to seek informal health care. For example, Australian studies have identified women with type-2 diabetes or cardiovascular disease as more likely to use herbal or nutritional products than men with these conditions [6]. In addition, a large US study of adults aged 45 years and older (N= 30,785) found women with a diagnosis of arthritis were more likely than women without such a diagnosis to use herbal or nutritional products [16]. Another study of Australian women aged 18-23 (N=7,164) identified women diagnosed with depression as more likely to use herbal and nutritional medicines when compared to women without depression [17]. Overall, research has found women who use informal care, such as herbal and nutritional medicine, are more likely to be middle-aged or older, better educated and more financially secure compared to non-users [6, 18].

Nevertheless, very little is known about the extent and details of informal health care use for chronic illness. Women may not always disclose their use of informal health care to their medical provider for a variety of reasons, including the belief that it is natural and consequently safe, and concern about their medical provider’s reaction [19]. This is especially problematic for ingested products that could interact with conventional medications to either reduce or increase drug activity [20]. It is also important to understand the extent of women’s use of informal health care for chronic illness and how this intersects with conventional care; for example, do women more commonly utilise one treatment type or choose to use multiple practices and products in parallel? This is a significant research gap. It is important to understand *all* health seeking behaviours of woman with chronic illness, including the relationship between women’s formal and informal health seeking behaviour in order to ensure safe, effective and fully coordinated patient care. Improved coordination of patient care may also reduce the burden of chronic illness upon individuals, communities and the health care system [21]. Consequently, this paper presents findings from the first study to describe a broad range of both formal and informal health care (and how they relate) as used by Australian women aged 45 years and over who have been diagnosed with one of five chronic illnesses in response to the following research questions:

1. How do middle-aged and older women utilise formal and informal health care to manage chronic illness?
2. Is type of informal health care used associated with the type of health care provider consulted?
3. Is type of informal health care used associated with health practitioner communication about such use?

## Methods

### *Study design and participants*

This paper reports on a sub-study of The Sax Institute's 45 and Up Study. The 45 and Up Study is the largest study of healthy ageing conducted in the Southern Hemisphere and the baseline questionnaire collected information from 266,848 men and women aged 45 and above who reside in the state of New South Wales, Australia. The 45 and Up Study is described in detail elsewhere [22], but briefly, individuals aged 45 years and above and resident in the State of New South Wales were randomly selected from the Department of Human Services enrolment database, which provides virtually complete coverage of the general population. Participants entered the study by completing a baseline postal questionnaire and providing written consent to have their health followed over time.

For the sub-study reported in this paper a random sample of 4,000 women who identified in the 45 and Up Study baseline survey they had been diagnosed by a doctor as having a chronic illness (comprising 800 women in each illness group—asthma, depression, diabetes, osteoarthritis, or osteoporosis) were mailed a questionnaire. Sub-study recruitment was conducted between September and December 2016 and a total of 1,932 (48.3%) women participated in the sub-study—comprising 376 with asthma, 362 with depression, 394 with diabetes, 406 with osteoarthritis, and 394 with osteoporosis.

The 45 and Up study and the sub-study reported on in this paper were approved by the University of NSW Human Research Ethics Committee, the sub-study was also approved by the



University of Technology Human Research Ethics Committee in accordance with the Declaration of Helsinki.

**Demographic Characteristics**

Demographic measures included age, education (no formal schooling, school only, trade, apprentice, diploma, university degree) and marital status (single, married/de facto, separated, divorced, widowed). Area of residence was defined using the ARIA+ remoteness score, which uses postcode to determine road distances to service centres, and thus women were categorised as residing in either a major city, inner regional area, or outer regional/remote area (AIHW, 2004). As a measure of income, women were asked how they managed on their available income ('it is impossible', 'it is difficult all the time', 'it is difficult some of the time', 'it is not too bad', 'it is easy').

**Formal Health Practitioner Use**

The women were asked if they had consulted with a range of health care practitioners for their chronic illness, in the previous 12 months, including medical doctors (general practitioner, medical specialist, hospital doctor) and allied health practitioners (nurse, pharmacist/chemist, counsellor, psychologist, dietitian, physiotherapist, occupational therapist).

**Informal Health Care Use**

Women were asked about their use of informal health care to assist in managing their chronic illness over the previous 12 months. This included consultation with an acupuncturist, chiropractor, naturopath/herbalist, homeopath, massage therapist, meditation instructor, yoga instructor, nutritionist, osteopath, and traditional Chinese medicine practitioner over the previous 12 months. The women were also asked if they had used a range of health products or practices specifically for their chronic illness over the previous 12 months, which included use of aromatherapy oils, herbal medicines, homeopathic remedies and nutritional supplements (i.e. multivitamins, chromium, glucosamine/chondroitin, calcium, cod liver oil, fish oil, cinnamon, vitamin D) as well as undertaking self-directed meditation (without an instructor), self-directed yoga (without an instructor) and physical activities/exercise (referred as physical activity).

Women reporting use of one or more of these health products or practices were subsequently asked to indicate whether this use was recommended by a medical doctor, allied health practitioner or other health care practitioner and if so, whether the practitioner monitored their use of the product or practice. Those women reporting use of one or more of the health products or practices were also asked if they talked to a healthcare practitioner about such use.

### ***Statistical Analyses***

The descriptive statistics employed included means and standard deviations (SD) for continuous variables and frequencies and percentages for categorical variables. A chi-square test was used to examine the association between two categorical variables. Statistical significance was set at  $p < 0.05$ . Adjustments were made to the p-value based on Bonferroni correction for each test of association. All statistical analyses were undertaken using Stata 14.1. Note that seven cases were excluded from the analyses due to significant missing data in their questionnaires, leaving total of 1,925 participants.

## **Results**

### ***Participant characteristics***

The average age of participants was 69.0 (SD=8.9) years, ranging from 53 to 95 years. The majority of the women resided in a major city (48.2%), with 39.7% residing in an inner regional area and 12.1% in an outer regional area. Most of the women were married or in a defacto relationship (61.1%), while 31.0% were separated, divorced or widowed and 7.9% were single. A university degree was attained by 29.4% of the women, with 30.0% completing a trade/apprenticeship or diploma, and 40.6% having no formal education or attended school only. In terms of their ability to manage on available income, 66.9% of the women indicated they had little or no difficulties, 22.3% indicated they had some difficulties, and 10.8% indicated it was difficult or impossible all of the time.

### ***Use of informal health care products and practices***

The use of informal health care products and practices for a specific chronic disease is presented in Table 1. Overall, 53.7% of the women used some type of informal health care practice

or product for their chronic illness; women with osteoporosis being the highest users of these products and practices (73.3%), followed by women with osteoarthritis (71.5%), depression (51%), asthma (33.1%), and diabetes (37.8%). In terms of specific informal products and practices, the highest users of herbal medicine were women with depression or diabetes. Women with depression reported the highest use of self-directed meditation and/or aromatherapy oils. Physical activity and/or nutritional supplements were more commonly used by women with osteoarthritis or osteoporosis. Conversely, women with diabetes were much lower users of self-directed yoga, meditation, and nutritional supplements.

**Informal health care and associations with type of health care provider**

Table 2 shows the association between use of informal products and practices and consultation with different health care provider types (both formal and informal). Overall, those women who use informal health care products and practices are significantly ( $p<0.001$ ) more likely to also consult with either a medical doctor, allied health practitioner, and/or informal health care practitioner, compared to women who are non-users of informal health products or practices. In terms of specific health product and practice use, there was no association between use of specific informal products or practices and consulting a medical doctor. A greater percentage of women who use aromatherapy oils ( $p<0.001$ ), herbal medicine ( $p<0.001$ ), homeopathy ( $p=0.003$ ), meditation ( $p<0.001$ ), physical activity ( $p<0.001$ ), and/or nutritional supplements ( $p<0.001$ ) also consulted with an allied health practitioner, compared to women who do not use these products and practices. Similarly, women who used any type of informal health product or practice were more likely to consult with informal health care providers, compared to those who did not use those informal health products or practices.

**Communication with health care providers**

Physical activity was the product/practice most commonly recommended by each health care practitioner type followed by nutritional supplements. However, much of the informal health products and practices used by these women were not recommended by a health care practitioner

and a very small proportion of informal health product and practice use was monitored by a health care practitioner. Communication with any health care practitioner regarding the use of homoeopathic remedies (96.3%), herbal medicines (66.9%), and nutritional supplements (68.2%) was relatively high. In contrast, communication with any health care practitioner about use of aromatherapy oils (41.7%), self-directed meditation (41.5%) and self-directed yoga (44.7%) was lower. Communication with only general practitioners about use of homoeopathic remedies and herbal medicines were 40.7% and 36.6% respectively, and communication with an allied health practitioner about any type of informal health care was relatively low (<19%). See Table 3 for summary statistics.

## Discussion

This paper reports findings from the first study to investigate both formal and informal health seeking behaviours of Australian women 45 years of age and older diagnosed with either depression, diabetes, asthma, osteoarthritis, or osteoporosis. Our analyses reveal a number of important findings relating to significant public health challenges for self-care management and prevention of chronic illness [8].

Our study shows that women with chronic illness are not using informal health products and practices at the expense of consultations with formal health care providers. Indeed, women using informal health products and practices consulted with all health practitioners more frequently compared to non-users of informal health treatments. This is consistent with the majority of previous research focused on other clinical population samples identifying that women employ informal health products and practices to complement their formal health care, and are more likely to use formal health services than women who do not use informal health products and practices [6, 23, 24]. It is suggested that women with chronic illness who actively engage in a range of self-care behaviours have a greater ability to reflect on their health status and health care experience, which assists them to make decisions that inform their health seeking behaviour [8]. Patients who are able to reflect on their self-care (e.g. evaluate effectiveness and monitor symptoms) have also been

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found to have good relationships with their health practitioners who provide them with education and support [8, 25], and having trust in a health practitioner has been found to predict health seeking behaviour [26].

Some of our study findings relate to undertaking physical activity, having potentially significant implications for public health. First, the majority of women reported not using physical activity to help manage their chronic illness. Physical activity was also more commonly recommended by general practitioners compared to both allied and complementary medicine practitioners. However, we also found a large number of women were not recommended physical activity by any health practitioner for their chronic condition, and it was much less frequently monitored by any health practitioner. These findings are important given that a lack of physical activity is critical for the prevention and treatment of chronic disease, and health practitioners are expected to promote physical activity to their patients [14, 27]. Our findings are consistent with previous research reporting low rates of general practitioner recommendations for exercise in an Australian general population sample [28]. Consequently, more research is needed to determine how health practitioners can be supported to better promote physical activity in primary health care to women with chronic illness.

The majority of informal health products and practices used by the women in our study were self-prescribed (not recommended by a health care practitioner), and approximately 40% of the women did not communicate with any health practitioner about using physical activity to manage their chronic illness. These findings align with previous research reporting that women are more likely not to seek advice from their doctor before using informal health treatments [19], and that they tend to primarily rely on friends and family rather than health practitioners to inform their decisions about such use [29]. Moreover, our study identifies women’s communication with health practitioners as varied depending on the type of health practitioner consulted and the type of product or practice used, and a substantial number of women report no communication with any health practitioner about their informal health care choices. Decision-making related to health

1 seeking and self-care for chronic illness is complex and requires consultation with health  
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3 practitioners (formal and informal) who can provide women with education about evidence-based  
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5 treatments and assist with skill development to ensure patient self-efficacy for self-care  
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7 management [25, 30]. Lack of communication with health practitioners is particularly concerning as  
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9 people who engage in evidence-based self-care have better health outcomes [25].  
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14 Given the potential direct and in-direct risks associated with the concurrent use of formal  
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16 and informal health care [20] and how these risks may be exacerbated by a lack of coordination and  
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18 communication in patient care, it is important that future research examines the enablers and  
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20 barriers to effective information exchange between patients with chronic illness and their  
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22 practitioners regarding all their health seeking behaviours. It is recommended that health  
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24 practitioners aim to establish strong therapeutic relationships with their patients that facilitate  
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26 supportive communication, skill development, and shared decision-making to enable safe,  
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28 coordinated care for the chronically ill [25, 26]. Future research should also aim to develop strategies  
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30 that eliminate barriers preventing patient communication such as poor health literacy, language and  
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32 cultural differences [31].  
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### 36 **Limitations**

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39 There are limitations to our study that need consideration. First, this is a cross-sectional  
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41 study of women residing in New South Wales and it is important to be cautious in generalising the  
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43 results to the broader Australian population. Second, each of the chronic disease diagnoses and use  
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45 of informal health care were self-report measures, which may be affected by recall bias. Third, while  
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47 our study included five chronic diseases that have been identified as national health priorities by the  
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49 Australian government [32], it did not include other prevalent chronic conditions such as  
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51 cardiovascular disease or cancer, or other patient populations—these conditions should be the focus  
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53 of future research to gain an understanding of health care use and treatment overlap in women  
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55 middle-aged and older. Finally, the informal health care use described in this study reflects a  
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57 regulated health care system that is unique to Australia that may not reflect that of other countries.  
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**Conclusion**

Women in our study used a range of informal health products and practices to manage chronic illness. Many of these women did not communicate with their health care providers about their use of informal health care products and practices, and the majority of these health care behaviours were not monitored by any type of health practitioner. Informal health care use has the potential to improve the quality of life for women with chronic illness and prevent future ill health. However, the failure of women and health practitioners to discuss and monitor informal health care raises the possibility of direct and indirect risks associated with certain forms of concurrent use.

**Acknowledgements**

This research was completed using data collected through the 45 and Up Study ([www.saxinstitute.org.au](http://www.saxinstitute.org.au)). The 45 and Up Study is managed by the Sax Institute in collaboration with major partner Cancer Council NSW; and partners: the National Heart Foundation of Australia (NSW Division); NSW Ministry of Health; NSW Government Family & Community Services – Ageing, Carers and the Disability Council NSW; and the Australian Red Cross Blood Service. We thank the many thousands of people participating in the 45 and Up Study, and especially those women participating in the present sub-study.

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**Conflict of Interest**

The authors declare there is no conflict of interest.

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Table 1. The use of informal health products/practices for a specific chronic disease.

Products / Practices		Asthma (n=375)	Depression (n=361)	Diabetes (n=392)	Osteoarthritis (n=404)	Osteoporosis (n=393)	Total (n=1,925)	p-value
		n (%)						
Aromatherapy oils	Yes	11 (2.9)	35 (9.7)	13 (3.3)	27 (6.7)	10 (2.5)	96 (5.0)	<0.001
	No	364 (97.1)	326 (90.3)	379 (96.7)	377 (93.3)	383 (97.5)	1,829 (95.0)	
Herbal medicine	Yes	15 (4.0)	31 (8.6)	52 (13.3)	31 (7.7)	16 (4.1)	145 (7.5)	<0.001
	No	360 (96)	330 (91.4)	340 (86.7)	373 (92.3)	377 (95.9)	1,780 (92.5)	
Meditation-self	Yes	32 (8.5)	60 (16.6)	24 (6.1)	44 (10.9)	33 (8.4)	193 (10.0)	<0.001
	No	343 (91.5)	301 (83.4)	368 (93.9)	360 (89.1)	360 (91.6)	1,732 (90.0)	
Yoga-self	Yes	22 (5.9)	23 (6.4)	7 (1.8)	16 (4.0)	26 (6.6)	94 (4.9)	0.003
	No	353 (94.1)	338 (93.6)	385 (98.2)	388 (96.0)	367 (93.4)	1,831 (95.1)	
Physical activity	Yes	69 (18.4)	108 (29.9)	88 (22.5)	171 (42.3)	165 (42)	601 (31.2)	<0.001
	No	306 (81.6)	253 (70.1)	304 (77.5)	233 (57.7)	228 (58)	1,324 (68.8)	
Nutritional Supplements	Yes	88 (23.5)	106 (29.4)	66 (16.8)	230 (56.9)	242 (61.6)	732 (38.0)	<0.001
	No	287 (76.5)	255 (70.6)	326 (83.2)	174 (43.1)	151 (38.4)	1,193 (62.0)	
Total	Yes	124 (33.1)	184 (51.0)	148 (37.8)	289 (71.5)	288 (73.3)	1,033 (53.7)	<0.001
	No	251 (66.9)	177 (49.0)	244 (62.2)	115 (28.5)	105 (26.7)	892 (46.3)	

Note. Use of homeopath remedies were not included in the table as all cell values were < 5, as per 45 and Up Study policy.

Table 2. Associations between use of informal health products/practices and consultations with medical doctors, allied health practitioners, and informal health practitioners.

Informal health products/practices		Consulted medical doctor			Consulted allied health practitioner			Consulted informal health practitioner		
		Yes	No	p-value	Yes	No	p-value	Yes	No	p-value
		(n=1,379)	(n=546)		(n=627)	(n=1,298)		(n=359)	(n=1,566)	
		n (%)			n (%)			n (%)		
Aromatherapy oils	Yes	79 (5.7)	17 (3.1)	0.02	48 (7.7)	48 (3.7)	<0.001	49 (13.7)	47 (3.0)	<0.001
	No	1,300 (94.3)	529 (96.9)		579 (92.3)	1,250 (96.3)		310 (86.3)	1,519 (97)	
Herbal medicine	Yes	115 (8.3)	30 (5.5)	0.03	67 (10.7)	78 (6.0)	<0.001	68 (18.9)	77 (4.9)	<0.001
	No	1,264 (91.7)	516 (94.5)		560 (89.3)	1,220 (94.0)		291 (81.1)	1,489 (95.1)	
Homeopathic Remedies	Yes	21 (1.5)	6 (1.1)	0.48	16 (2.6)	11 (0.9)	0.003	20 (5.6)	7 (0.5)	<0.001
	No	1,358 (98.5)	540 (98.9)		611 (97.4)	1,287 (99.1)		339 (94.4)	1,559 (99.5)	
Meditation-self	Yes	137 (9.9)	56 (10.3)	0.83	87 (13.9)	106 (8.2)	<0.001	88 (24.5)	105 (6.7)	<0.001
	No	1,242 (90.1)	490 (89.7)		540 (86.1)	1,192 (91.8)		271 (75.5)	1,461 (93.3)	
Yoga-self	Yes	66 (4.8)	28 (5.1)	0.75	24 (3.8)	70 (5.4)	0.14	48 (13.4)	46 (2.9)	<0.001
	No	1,313 (95.2)	518 (94.9)		603 (96.2)	1,228 (94.6)		311 (86.6)	1,520 (97.1)	
Physical activity	Yes	454 (32.9)	147 (26.9)	0.01	247 (39.4)	354 (27.3)	<0.001	205 (57.1)	396 (25.3)	<0.001
	No	925 (67.1)	399 (73.1)		380 (60.6)	944 (72.7)		154 (42.9)	1,170 (74.7)	
Nutritional Supplements	Yes	543 (39.4)	189 (34.6)	0.05	276 (44.0)	456 (35.1)	<0.001	233 (64.9)	499 (31.9)	<0.001
	No	836 (60.6)	357 (65.4)		351 (56.0)	842 (64.9)		126 (35.1)	1,067 (68.1)	
Total	Yes	772 (56.0)	261 (47.8)	0.001	389 (62.0)	644 (49.6)	<0.001	298 (83.0)	735 (46.9)	<0.001
	No	607 (44.0)	285 (52.2)		238 (38.0)	654 (50.4)		61 (17.0)	831 (53.1)	

Note. P-values based on Bonferroni correction.

