

Exploring factors influencing osteoporosis prevention and control: A qualitative study of Iranian men and women in Australia

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Abstract

Objective: To explore the understanding of osteoporosis risk factors and barriers that influence osteoporosis prevention and control in order to better inform the development of culturally appropriate osteoporosis preventive strategies.

Methods: This qualitative study was based on data collected from 5 focus groups, 10 individual interviews and 3 opportunistic group discussions of Iranian men and women living in Australia. A thematic analysis approach was used and data were managed with a computer-assisted program. Data were collected over 1 year in community settings chosen by participants.

Results: The participants had insufficient understanding of osteoporosis risk factors and its implications for their health as they age. There were minor misconceptions about the causes of the disease and how it could be prevented and controlled. Many participants confused osteoporosis and osteoarthritis. Where they did indicate some knowledge of preventive actions, they perceived many obstacles to their undertaking preventive behaviours.

Conclusions: These data suggest that factors adversely influencing osteoporosis prevention and control have their root in misconceptions about osteoporosis and its risk factors, and psychosocial and structural barriers to taking preventive actions. These findings provide insights into barriers that need to be overcome if preventive strategies and intervention programs can be developed to reduce the overall burden of osteoporosis in the community.

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1. Introduction

Osteoporosis is a common disorder in the elderly, and represents one of the most significant public health

problems in the world, because it predisposes to fractures with minimal or no antecedent trauma. These fractures are, in turn, associated with reduced quality of life [1], increased morbidity and mortality [2], and high health care costs [3]. Despite the magnitude and seriousness of the problem, osteoporosis

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is still underdiagnosed and undertreated in Australia [4].

Prevention and treatment of osteoporosis involves a wide range of strategies including physical activity, avoiding smoking and excessive alcohol intake, healthy diet, adequate calcium intake [5], taking appropriate medications, and measures to prevent falls [6]. However, the effectiveness and adherence to these preventive and treatment measures is dependent on a complex interaction between psychological, cultural, environmental and behavioural factors. For instance, lack of knowledge and mistaken beliefs have been found to influence calcium intake, exercise [7] and other osteoporosis preventive behaviours [8]. Concerns about adverse effects such as gas, bloating, and constipation were cited as potential reasons for lack of adherence to calcium supplementation [9]. In a recent study among African–American women and Hispanic white women, it was found that lack of trust in medications, doubt about physicians' competence and proactive patient behaviours were among the reasons for lack of adherence to osteoporosis treatment [10].

Cultural factors can affect decisions concerning preventive practices [11] and treatment [12]. Since beliefs influence motivations to take part in preventive health behaviours and services, prevention and treatment advice should encompass an individual's cultural health beliefs [11]. Lack of understanding of culture can block acceptance of evidence-based health information [13]. Health professionals might find that working with traditional beliefs rather than confronting or dismissing them could influence patients or communities to be much more receptive to them taking recommended action.

Misinformation and confusion about cervical cancer risk factors and preventive strategies along with psychocultural and structural barriers have been reported as underlying factors for low rates of screening among Korean–Americans [14]. Previous researchers have reported that ethnic minorities are less engaged in osteoporosis health preventive practices [11,15]. In Australia, knowledge concerning osteoporosis risk factors and preventive strategies is particularly deficient in those from non-English-speaking backgrounds [15,16] and they adopt minimal osteoporosis preventive behaviours [15,17]. Although these studies revealed what was known and practiced by participants, they were unable to explain underlying factors for these

low rates of preventive behaviours from the points of view of individuals, and the extent to which cultural and health beliefs might exert an influence over them taking up recommended preventive practices.

The aim of this study was therefore to qualitatively explore the understanding of osteoporosis risk factors and barriers that might influence osteoporosis prevention and control, in order to build a richer picture of the perceptions and experiences of one group of immigrants to Australia from a non-English-speaking background. This study complements a recent survey of Iranian–Australians using quantitative measures [16].

2. Methods

In order to best address the purpose of the study, a qualitative inquiry was undertaken. It was anticipated that answers to open-ended questions would lead to better understanding of the issues we wanted to address, clarifying the perspectives of the participants.

2.1. Data collection, participants and settings

Perceptions were tapped through a variety of data collection methods. Initially, five focus groups were conducted with Iranian–Australian individuals who had earlier participated in a survey in which the aim was to assess osteoporosis knowledge, health beliefs and self-efficacy [16]. The original sample was recruited via a media campaign using newsletters, notice boards in community halls as well as word of mouth at community centres. The survey included 42 men and 131 women (aged between 35 and 77 years). All participants were born and raised in Iran, primarily spoke Persian, but had been resident in Australia for various lengths of time.

From the 173 participants in the earlier survey, 159 (92%) had agreed to be contacted by telephone. The 5 focus groups composed of from 5 to 6 participants aged between 35 and 70 years were assembled from these contacts. The participants in the focus groups were 22 women and 5 men. In addition to the focus group discussions, semi-structured interviews were also undertaken with 10 women aged between 35 and 56 years to extend our findings as the data had not yet saturated. Participants had various different educational levels, with approximately half of them having a university

education. The majority of individuals were married and had children.

The focus group discussions lasted between 2 and 3 h, the interviews averaged 40 min. Both focus groups and individual interviews were conducted in locales convenient to the participants. Finally, data were also collected opportunistically when the first author was asked to present on osteoporosis to two senior citizen groups, and one Iranian–Australian community group. Data collection continued until saturation had been reached and no new themes emerged [18]. The study was approved by the University of New South Wales' Human Research Ethics Committee, and written informed consent was obtained from each participant.

2.2. Topic guide

Topics discussed included participants' understanding of osteoporosis risk factors, its prevention and early treatment as well as views on possible ways to prevent this disease. Questions posed to participants included:

- What do you know about osteoporosis?
- What are the risk factors for osteoporosis?
- What preventive actions or treatment might you try if you are concerned about osteoporosis?
- What are possible ways to prevent osteoporosis?
- What are the barriers for undertaking osteoporosis preventive behaviours?

2.3. Translation and substantiation

All focus groups, individual and group interviews were conducted in Persian (Farsi), the first language of participants. The focus groups and individual interviews were tape-recorded, transcribed and translated into English [19,20], while the group interviews were documented by note taking and then key parts of the notes were translated. The transcripts were re-checked against the recordings and notes by the first author since one translator working with the data maximizes dependability of the data [21]. The interviews were translated into English in order to make the data accessible to the other members of the research team [22] for discussion. About a fifth of these translations were sent to an independent bilingual translator and the two sets of translations were then compared for consistency

[23]; no significant differences in meanings were identified. The interpretation of the data was checked with one member of each focus groups and two randomly selected interviewees to compare these perspectives with that of the research team.

2.4. Data analysis

An iterative approach to data analysis was adopted, in which analysis began after the first focus group, to allow emerging themes to be explored in subsequent interviews and group discussions. Initial coding was done by the first author, with the other authors later providing their perspectives leading to further analysis, and confirmation of interpretation of data. A thematic analysis approach [24] was used, with the group being the unit of analysis in the case of the groups, and the individual as unit in the case of the individual interviews. NVivo version 2.0 (QSR International, Melbourne, Australia) was used for the management of the data.

3. Results

Discussions triggered by the use of the topic guide questions helped to elicit participants' perceptions regarding how they understood osteoporosis risk factors and overall cause. Textual analysis revealed four major themes as follows: understanding of disease, perception of causes, preventive behaviours, and obstacles to preventive actions.

3.1. Disease understanding

When asked how they could best describe osteoporosis, participants used the terms "porousness of bone" (*pookie ostekhan*). The majority of participants frequently expressed the view that the disease was because of lack of dietary calcium intake. Some women cited the disease as "*brittle bone*": "I've heard about this disease which when you get it, the moment you fall down, you can easily break your bones".

Although falls prevention is an important issue in any osteoporosis preventive strategy, it was not discussed by participants. The consequences of osteoporosis also were not specifically mentioned. However, some participants expressed a fear of osteo-

porosis because they had some notion of its severity and were concerned about the consequence of becoming dependent on others as illustrated by one woman explaining—“This disease is very important because it comes to you when you’re very old, weak and alone . . . I am concerned about becoming frail . . . I don’t want to rely on others”.

There appeared to be considerable confusion about how osteoporosis is manifest. Several women confused osteoporosis with joint conditions. One woman stated: “I have back pain . . . I am not sure if it is porousness of bone or arthritis but it [pain] is related to my bone”. However, a second woman stated astutely: “This disease is different from heart disease or diabetes because it doesn’t have any symptoms. I think people and even physicians and policymakers care [more] about diseases which have symptoms such as heart disease”.

3.2. *Perceived causes*

Participants generally had insufficient knowledge about osteoporosis risk factors. As one participant explained: “We don’t know much about the disease. This disease is unknown for us. We want to know if this disease causes pain or is it like cancer and only when it occurs do we feel it?”. Oral information from friends and relatives was commonly cited as their primary source for the knowledge they did possess. A few participants correctly noted certain risk factors such as hormonal changes, advancing age, use of corticosteroids (*corton*), premature menopause (*removal of the ovary*), and physical inactivity.

Some participants referred to a phenomenon called silent culture which seemed to be a concern amongst some Iranians. Although their idiomatic way of expressing this belief was not well translatable from the Persian into English, it was clear they believed that there was a link between unexpressed emotional pain (*dard* or *narahati*) and osteoporosis. To participants, emotional pain included the state of being sad (*ghamgin*) and depressed (*afsordegi*). They believed that emotional pain (*dard* or *narahati*) is associated with developing disease in general and osteoporosis in particular. “We don’t often talk about our emotional problem (*narahati*) . . . we might talk about our physical problems but not about emotional problems (*narahatiha*) . . . I think these *narahatiha* can damage our bones”. Another woman said: “. . . we keep everything

inside we’ll get sick and it will affect our bones . . . it burns our bones from the inside”.

Although the majority recognized the importance of calcium intake, they did not correctly identify calcium-rich foods nor were they aware of the recommended amount of calcium intake. For example, some stated they believed meat or chicken were good sources of calcium. Whilst most thought that they could have an increased risk of osteoporosis because of a positive family history of the disease, others did not perceive themselves to be at risk because of misconceptions about such things as breastfeeding or the absence of a family history of osteoporosis—“There is no porousness of bone in our family so I would not get it and I am not concerned”.

Amongst those who confused the disease with arthritis, a few tended to perceive an association between disease and the weather. They believed there is an association between moisture and the disease, as one woman stated, “It is about diet and weather. I mean humidity . . .”.

While the association between smoking and lung cancer was acknowledged, many participants were not aware of the link between smoking and bone health. One man and one woman who were smokers strongly disagreed that cigarette smoking was harmful to bones. Only one female smoker acknowledged that it increased the risk of osteoporosis, but from the discussion that took place, it appeared that the rest of the participants had little idea about a relationship between smoking and osteoporosis.

Diet, particularly healthy diet such as vegetables, was considered to have a more positive and considerable effect on bone than exercise. In addition, the recommended exercise for osteoporosis was not entirely understood, with the majority of participants stating that they thought swimming was an effective form of exercise to reduce its risk. Among those who were willing to exercise some cited that lack of appropriate exercise facilities for women was a barrier: “We don’t have here suitable places [only for women] to exercise”. It appeared that participants often found walking the preferred form of exercise because of convenience.

3.3. *Preventive behaviours*

Probably due to lack of clarity as to what causes osteoporosis, some participants did not see the value

in taking preventive actions. A typical view was expressed by a participant when she said “While we are young . . . we don’t do anything to prevent porousness of bone because it occurs after menopause”. Some felt more comfortable denying their susceptibility—“I am afraid of diagnosis of the disease as I know I can’t do much about it”. Most who did attempt to take preventive measures took medications, either conventional or complementary. Some women expressed a preference for taking herbal medications or herbal remedies because they believed that the latter were more “natural” and had fewer side effects. Many noted the confusion generated by the mass media when colourful stories have accentuated the potential negative effects of some medications such as vitamins or hormones. Fewer participants considered implementing lifestyle changes particularly exercise due to they perceived difficulty in commencing a new habit.

3.4. *Obstacles to preventive actions*

Interviewees discussed the barriers they perceived to them taking personal action to prevent osteoporosis. Misunderstandings between doctors and patients were frequently mentioned by participants as obstacles to communication, as was the lack of information about the condition available in their first language. Some participants explained that the information was not provided in adequate detail or was difficult to understand. They also had difficulties asking questions or expressing their problems in English and understanding some of the advice given to them by their doctor—“My doctor told me I should drink milk, but I just couldn’t drink it because I am allergic to milk, it makes my stomach upset, but I do not know what to do”. Another stated: “We must have more information about this disease. They give us different options and leave it to us to decide, and when we ask which one is better they tell us it is up to you. How it’s up to us then we don’t know . . . they don’t care”. One woman was particularly concerned, saying “. . . another problem is sometimes they tell us about our disease very directly, particularly bad things such as cancer . . .”. Many nodded when a participant complained that “Nobody talked to me about porousness of bone, but I know calcium is good for my bone and I am taking it on and off”.

One man and some women mentioned living conditions as a barrier to sunlight exposure and vitamin

D production: “Here [Australia] is different to Iran [Tehran], because there, there are swimming pools only for women”. Another stated—“In Iran, before there were no apartments and most people like my mother had backyards and they had more sun exposure but now that is changed, and more people are living in apartments and don’t have enough sun exposure”. However, others disagreed, with one woman stating “My face and hands are exposed to the sun when I get out. I think a few minutes of direct sunlight every day are enough”.

The absence of symptoms was mentioned as a potential barrier. Some participants thought they might see a physician for a disease with symptoms obvious to them, but not for a “silent disease”. Those that did see a doctor did not expect much preventive advice—as one participant saw it, “The problem is that most doctors are busy . . . they don’t have time to advise on lifestyle . . .”. Some doubted the doctor’s ability—“I was diagnosed with porousness of bone . . . my doctor only advised me to exercise and drink milk, but I asked my sister who also had osteoporosis, and she told me I should take calcium tablets and vitamin D . . .”.

Among women taking medications as a preventative, the dose and form of the medications were felt to be barriers: “I have not taken my calcium and vitamin D tablets because it is quite big, and they are difficult to swallow”. Another said “. . . If it [calcium tablet] was only one dose per month I would be more likely to take it. I forget to take my calcium tablet. I’d like to take it weekly . . .”.

4. Discussion

The present study, by using qualitative research methods, has attempted to illuminate the complementary study’s quantitative findings found through a survey with a sample derived from the Iranian population. Although the nature of this small qualitative investigation means these results will be more indicative than definitive, the richer understanding of the barriers to preventive actions and perceptions of some members of this population has the potential to help in initiating innovative and appropriate preventive interventions. The study found that misunderstanding of osteoporosis itself, of its risk factors, psychosocial and structural barriers and lack of confidence in preventive intervention efficacy are likely contributory factors to lack of

action as seen from the patients' and community's perspectives.

It is generally accepted that post-menopausal women with a high-risk profile should have a bone mineral density scan for diagnosis of osteoporosis. Moreover, women found to have osteoporosis (i.e., diagnosed with a low bone mineral density) or with a history of fracture, should be considered for treatment. However, recent studies have shown that high-risk women are neither being diagnosed nor treated [4,25]. In a study in a managed-care setting, Freedman et al. found that only 5% had a bone mineral density scan and only 23% were initiated on hormone replacement therapy, calcitonin, or bisphosphonates [26]. The situation for hip fracture is more disturbing. In a study of 502 hip fracture patients in hospital setting, only 14% underwent a bone mineral density scan, 13% received calcium/Vitamin D, and only 18% received hormone replacement therapy, calcitonin, or bisphosphonates [27].

Why are women with osteoporosis or at risk of fracture not seeking treatment? A number of themes identified from this study such as lack of trust in the efficacy of medications, concern about adverse effects of medications, and doubts about physicians' competence have also been identified in previous studies as potential factors for the lack of adherence to osteoporosis treatment in African-American and Hispanic white women in the United States [10]. On the other hand, beliefs of benefits of antiresorptive therapies, perception of susceptibility to osteoporosis and fewer barriers to drug treatments have been shown to be strong predictors of antiresorptive therapy use [28].

A good doctor-patient relationship could reduce misunderstandings and mistrust to allow more effective prevention and treatment. This is particularly important for non-English-speaking patients among whom English skills are limited. The present study identified that communication was a potential barrier to prevention of osteoporosis. This finding is consistent with a previous study, in which Iranian-American women had difficulties in communicating their problems to health care providers [29]. Our data suggests that doctors need to pay more care in articulating the diagnosis of serious disease to Iranian patients. In addition, as some of the participants expressed in this study, herbal remedies are used to for treatment of various diseases. Doctors may need to question their patients' use of herbal

medicine or traditional remedies to prevent the possibility of adverse reactions occurring with prescribed medications [30].

An interesting and unexpected finding was the participants' beliefs that emotional pain (*dard* or *narahati*) may contribute to depletion of bone density. Although they perceived an association between osteoporosis and depression [31], a number of people were unwilling to bring their emotional problems or depression to medical attention. In Iranian culture, "Pain" (*dard*) has a wide range of meaning including both physical and emotional pain. Sometimes it may be used for the expressing "*narahati*" [32]. Although Iranian people use this term (*narahati*) to express discomfort or unpleasant emotional and physical feelings, this concept is not fully translatable into English. In this study this word was used to indicate a negative emotion such as being depressed and sad which consequently can cause or exacerbate the disease. In Iranian culture, *narahati* is expressed in verbal or nonverbal forms, in idioms or not talked about it at all. People's views of their *narahati* affect whether they show or conceal it [30]. Although not all Iranians people articulate their *narahati* in the same way, and whether or not they choose to express their personal and private *narahati*, doctors will benefit by learning to listen and to interpret problems of their Iranian patients [30]. Exploring the causes of *narahati* was beyond this study, however acculturative stress and immigration issues have been cited in other studies as a potential cause [29,33].

The confusion between osteoporosis and osteoarthritis has been reported in previous studies [34]. While bone pain can be mistaken for osteoarthritis, many stress fractures can also result in bone pain. An intriguing finding of this study was the effect of weather on osteoporosis. However, this is perhaps due to the incorrect attribution of osteoporosis to osteoarthritis. Indeed, the belief is suggested to be linked to the way the mind was working rather than an actual effect [35]. Other researchers have shown a similar finding that perception of moisture is associated with the disease in Iranian older men and women who complain about the pains in their limbs [30].

The present study addressed an important subject in public health research in a group from a non-English-speaking background in an Australian setting. Many previous studies have reported low rates of preven-

tive behaviours among men and women, but most did not explore the underlying factors for these low rates from the points of view of individuals. This study was undertaken with due rigour, attaining data saturation through various data collection methods, careful member checking as analysis and interpretation evolved, and by enhanced cross-cultural communication through the first author being an Iranian and able to interact in a natural and culturally sensitive manner with participants. However, the present study has a number of potential weaknesses. The data cannot reflect a wide range of men's beliefs because of the few men participating. Since the interviews and group discussions were conducted with individuals with various length of residence in Australia, the levels of potential acculturation may have affected the women's views and this aspect need to be considered in interpreting data. Furthermore, exposure to the prior survey could have affected the views of the participants in increasing their awareness of the disease as a problem but it would be unlikely to influence their actual beliefs.

5. Implications

Identification of barriers to preventive measures and perceptions about risk factors is necessary for the development of public health programs for the prevention of osteoporosis. Intervention programs must be culturally appropriate to effectively address issues of particular concern. These can be based on those attitudes existing in the community with a focus on overcoming practical barriers to disease prevention. Potential for learning about the disease through informal information sources such as friends and relatives is generally high in non-English-speaking groups within English speaking countries. This has implications for wider community-level dissemination of appropriate information.

The importance of media coverage in obtaining information about the disease could be addressed in health promotion programs since these respondents indicated reliance on this source. In addition, health care providers could be educated to achieve cultural competence in counselling and discussion with people from diverse ethnic backgrounds to avoid fears and confusion, particularly where they have limited avail-

ability of information in the language of the patient, client or community member.

The present study's findings may help doctors, public health educators, social workers, and policy-makers to understand the critical role of effective culturally-based preventive strategies as well as immigrant needs particularly in this common public health problem.

In summary, these findings provide some insights into barriers that need to be overcome if preventive strategies and intervention programs can be developed to reduce the overall burden of osteoporosis in the community. The study is valuable for Iranian populations in Australia but even more importantly, it has implications for prevention with other non-English-speaking background people who may have different but no less influential cultural beliefs and practices which need to be exposed and dealt with constructively.

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