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Asthma management in Australian Arabic speakers

Asthma management experiences of Australians who are native Arabic-speakers.

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Abstract:

Objective: The aim of this study was to explore the asthma management experiences of people with asthma within the Arabic-speaking community in Australia. **Methods:** Semi-structured interviews guided by a schedule of questions were conducted with 25 Arabic-speaking women with asthma/carer of a child with asthma, recruited from medical practices and community centers in Melbourne, Australia. **Results:** Twenty-five Arabic-speaking participants with asthma or caring for those with asthma were interviewed. Interviews lasted on average 25 minutes. Most participants or those they were caring for did not have well-controlled asthma. Thematic analyses of the interview transcripts highlighted five key emergent themes: stigma, health literacy, non-adherence, expectations and coping styles. Findings indicated that many participants were not conversant about local information avenues or healthcare or facilities such as the Asthma Foundation or availability of Arabic translators during general practitioner (GP) consults. Many recent migrants were generally non-adherent with treatment; preferring to follow traditional folk medicine rather than consulting a GP or pharmacist. Some unrealistic expectations from

doctors/treatment goals were expressed by a few participants. Some parents of children with asthma reported disappointment with the fact that their children did not grow out of asthma.

Conclusion: Low health literacy and in particular knowledge about asthma, cultural beliefs, language, and migration-related issues may all be affecting the level of asthma control in the Arabic-speaking population in Australia. Measures to enhance asthma and health system literacy designed to be culturally concordant with the beliefs, expectations, and experiences of such populations may be key to improving asthma management.

Keywords

Asthma, Arabic, Migrants, Ethnicity, Management, Australia, Asthma Control.

Background:

Asthma is a common chronic inflammatory condition of the airways affecting about 300 million people worldwide [1]. In 2007, Australia had one of the highest prevalence rates in the world, with 10% of the population at the time diagnosed with asthma [2]. Australia is also a highly multicultural country with people from many culturally and linguistically diverse (CALD) ethnic backgrounds. Ethnicity may be thought of as a population group with shared identities based on nationality, ancestry, language, religion or cultures [3]. It is well known in the case of asthma, that prevalence, treatment response, exacerbation frequency and hospitalization rates vary across ethnic groups, even within those in the same healthcare system [2, 4].

Genetic variation is one obvious reason for the cultural and ethnic variance in the clinical features of asthma. *Pharmacogenetics*, for example, in the case of β_2 agonists, β_2 receptor polymorphisms (such as Arg16 to Gly (Gly16) and Gln27 to Glu (Glu27)) affect medication response and severity of asthma among populations [5,6]. Data suggest that people with the Gly 16 allele have a heightened initial response to β_2 agonists but this responsiveness deteriorates upon prolonged exposure [7,8]. β_2 adrenergic receptor polymorphisms may also be associated with variances in asthma symptom severity [9]. Recent data highlighted the association of the Gly16 allele with nocturnal asthma in a sample of Egyptian children [10]. *Pharmacokinetics* of

drugs also differ among ethnic groups due to differences in liver enzyme activity. The variation in metabolism may subsequently cause different side effects among ethnic groups [5,6, 11].

Genetic variation may also dictate how patients respond to different triggers – African Americans, for example, are possibly prone to a greater reduction in lung function resulting from smoking compared to European/Caucasian Americans smokers [12].

Other reasons for ethnic differences in asthma-related management and behaviors may result from cultural and health beliefs about asthma. For example, in a US study in 2012, some Latino carers of children with asthma indicated believing that using certain food types (hot/cold) could be a cure/treatment for asthma. There was a belief that ‘*hot foods*’ can cure certain health problems, while ‘*cold foods*’ can cure other diseases [13]. Data from these participants also suggested variable self-management; they reported taking their symptomatic children to clinics rather than following an action plan to manage asthma symptoms [13]. Similarly, in a study from New Delhi, India conducted with parents of children with asthma and children themselves, social stigma was one of the key factors affecting asthma management. Parents reported hiding their child’s asthma diagnosis from siblings, the child’s school and other social circles [14]. This was particularly the case for a female child, as parents did not want to affect their daughters’ future marriageability [14]. These parents also showcased fatalistic attitudes, which accepted the idea of having asthma as being “God’s will”, and not proactively managing the condition using

medication [14]. Many of these parents also expressed fears or concerns about using steroid based inhalers (steroid phobia) [14]. Similarly, results of a cross-sectional study conducted with pediatric caregivers attending an outpatient clinic in Riyadh, Saudi Arabia, indicated that parents believed that using asthma inhalers led to addiction, dependence and heart damage [15]. Culturally nuanced health/medication beliefs may, therefore, affect asthma management behaviors, as patients may have varied illness representations.

During the 1970 s and 1980 s, a large number of people of Arabic ethnicity migrated and settled in Australia [16]. In 2001, the Arabic language was one of the five most spoken languages, other than English, at home [16]. It is likely that many Arabic-speakers in Australia experience asthma, although the exact proportion of those with asthma is not known [2, 17]. Many may also not be fluent in English (Australia's official language), depending on time since migration, and therefore have varied health literacy levels. An Australian Adult Literacy and Life Skills Survey (ALLS) conducted in 2006 indicated that there was a lower level of health literacy amongst Arab migrants compared to those migrants who were born either in Australia or any English-speaking country [18]. Cultural and linguistic barriers are primarily highlighted in health disparities research, however in addition to cultural and linguistic barriers, in the case of Australians with an Arabic background, there may be other underlying issues compounding asthma management. For example, under-employment and post-war traumatic stress for refugees [19,20]. Data indicates

higher asthma prevalence and poorer management in ethnic groups such as Indigenous Australians, however, there are no studies exploring the experience, beliefs, asthma management behaviors or health needs of Arabic-speaking Australians living with asthma.

Aim: The aim of this study was to explore the experience and perspectives of Arabic-speaking people with asthma, who have low English proficiency (LEP), about their asthma management.

Method: Qualitative methods employing semi-structured in-depth interviews were used to achieve the aim of this study.

Setting and recruitment: This study was conducted Melbourne, Australia, with a convenience based purposive sample of participants with asthma or carers of those with asthma, recruited from various venues such as:

- 1) Arabic community organizations.
- 2) Medical practices and community pharmacies in select areas in Melbourne
- 3) Other community venues such as mosques.

The areas for recruitment were selected based on data from the Australian Social Health Atlas, identifying areas of relative multicultural density [21]. Recruitment from community organizations was initiated by presentation on asthma to Arabic-speaking people. Doctors and

community pharmacists were sent a project invitation, followed by a phone call, and requested to display project flyers on their premises. The flyer directed those who met inclusion criteria to contact the research team.

Participant Selection: Inclusion criteria for participants were that they had to be:

1. Arabic-speaking people with diagnosed symptomatic asthma or carers of someone else with diagnosed asthma and with low self-reported English language proficiency. This latter was gauged by asking “*How well do you speak and understand English*”. Responses of “*not well*” or “*not very well*” or “*not at all*” were deemed as low English language proficiency [22, 23]. Participants who responded “very well”, or “well” were excluded from the study, as they were deemed to be fluent in English. [It may be noted that this question is used to assess self-assessed English Language Proficiency in the Australian National Census as well [24].
2. Aged over 18 years old. If the patient was less than 18, the parent (or carer) was interviewed.

Potential participants were excluded if they were Arabic-speakers with asthma who were fluent in English, or if they significant cognitive disabilities or serious illness. Potential participants

who reported that they ‘rarely’ or ‘never’ experienced symptoms were also excluded based on the assumption that their experiences with asthma may not in that case be current or recent.

Asthma control in participants or those they were carers for was ascertained by asking participants four questions in the interview about: 1. frequency of symptoms needing reliever medications; 2. symptoms at night; 3. symptoms in the morning; and 4. activity-limitations posed by asthma. Participants’ responses were used to categorize them (or person they were carers for) as having good, partial or poor control as highlighted in Table 1, in accordance with the Australia National Asthma Council guidelines [25]. This data was collected as part of the patient’s asthma demographics, as it is recognised that the frequency and severity of symptoms may affect the perceptions and experience of people living with asthma.

For participants meeting criteria, written consent was sought and interviews conducted at times convenient to the participant. All interviews were conducted in Arabic and translated into English by a research team member who is a native Arabic-speaker, and verified by another NAATI (National Accreditation Authority for Translators and Interpreters) accredited translator/interpreter in the research team. A semi-structured interview guide, based on the literature and aims of the study was used to guide interviews. Interviews continued until

“saturation”, occurred i.e. when the collection of new data does not shed any further light on the issue under investigation [26].

Analysis:

The data were subjected to thematic analyses in a phenomenological paradigm. The thematic analysis process involved the iterative reading of the collected data for familiarization, then coding of emerging themes.

Twenty-five interview transcripts were independently coded by two authors (RA and BS) and the thematic collection was discussed at a team meeting with all authors. A robust debate about these themes and the meanings assigned to words occurred at this meeting with the third author being a certified Arabic translator; hence the thematic structure was examined both in the Arabic transcripts as well as the translated English version.

Results:

Participant demographics are highlighted in Table 2. Twenty-six interviews were conducted between April and October 2016. Most participants were recruited through Arabic community organizations and all interviews were conducted in Arabic. A majority of the participants were young to middle-aged adults. All participants were female, a greater majority had had asthma (or cared for a person with asthma) for over fifteen years. Most

of the participants had been residing in Australia for more than 10 years. Asthma self-assessment indicated more participants had poor control of asthma than good/partial control.

The final analysis yielded very rich data from which 5 themes were derived. Some of these themes were coalesced from several sub-themes as highlighted in Figure 1.

Themes and subthemes are briefly described within the text and are further illustrated descriptively with exemplar quotes from the data (Table 3). Each quote is followed by a number describing the participant code and whether the person with asthma in question had good, partial or poorly controlled asthma.

Theme 1: Stigma:

The two sub-themes within this theme include ‘*shame*’ and ‘*hiding from others*’. Having asthma was described as shameful or embarrassing repeatedly by participants. For example, experiencing symptoms of asthma or having to use medications in front of others were particularly reported to cause embarrassment. Parent participants who had a child with asthma indicated they did not like to talk about it with others, in fact, they hid the fact from others in their social circle. This appeared to stem from the feeling that ‘others’ thought asthma was contagious. Another reason for hiding asthma was because of a perception that the ‘Australian culture’ did not allow social discussion of disease or treatment experiences; in fact those with this perception were not open about their asthma even to family members or friends.

Theme 2: Health literacy:

‘Language barriers’ and *‘health and health system awareness’* were underlying concepts within this theme. Participants reported a preference to consult with Arabic-speaking doctors in Australia rather than English speaking doctors; this was because they could exercise freedom of expression in a language they were competent in, and not because they did not ‘trust’ English speaking Australia doctors. The use of medical jargon or terminology in English used by doctors was reported to be confusing by some participants.

The provision of free interpreters made within the Australian health-system was not usually availed of, as participants mistrusted interpretation skills of official interpreters.

Most participants’ responses suggested a lack of general health literacy or familiarity with the health-system. Most reported not having an asthma action plan provided by their doctor, or even knowing what an action plan was. A few participants mentioned owning action plans but not using them, as they felt they were experienced in asthma management. Further, some participants even reported not knowing what to do in the event of an asthma emergency. This was particularly the case with more recent migrants to Australia, although some long-term residents in Australia also mentioned that no one had informed them about asthma first-aid.

Even when participants were aware that they did not have enough information about asthma,

they did not appear to know about local health services that can help them beside their doctor. Some participants were not aware of consumer advocacy or information agencies such as Asthma Australia/National Asthma Council, which provide free educational materials/resources for consumers. Although translated resources from these organizations are available in many languages including Arabic, participants were not aware of accessing these, for example on the Internet.

Theme 3: Treatment Non-adherence

A majority of participants described using their therapy in a manner that was not likely to be adherent to health professionals' recommendations. Submerged within this theme were key underlying reasons for non-adherence to treatment, such as *beliefs, fear of side effects or addiction, steroid phobia and a lack of initiative to employ self-management skills*.

For example, some participants had beliefs about complementary medicines as being 'natural alternatives' and 'safer' than conventionally prescribed medications, and they preferred these alternatives. Some participants reported that they had stopped using asthma puffers for fear of side effects. The perception that asthma medications are addictive was another concern voiced by participants. This led to dose reduction and cessation of prescribed therapy for fear of long-term side effects. A few participants specifically had concerns about using steroids for asthma in their children. Finally, a few participants mentioned that being overwhelmed with

life problems and having other commitments left them with no time for asthma management activities such as following up with their child's school about using asthma medications before sports at school.

Theme 4: Expectations

'Unrealistic expectations from health care professionals' and *'unmet treatment expectations'* were key points evident within this theme. Most participants in the sample grappled with expectations about their treatment efficacy or what they expected their health professional to provide in terms of asthma care. A few participants stated for example that they do not seek regular reviews of their asthma with their doctor, as they never receive 'new treatments' and their treatment regimens were not changed between visits. Non-prescription of new medications appeared to participants as a reflection of doctors' inability to treat the disease. Some participants appeared not to be cognisant of the fact that asthma cannot be cured, but controlled, therefore given their asthma was not 'cured', repeat visits to the doctor for asthma reviews were considered futile. Contrary to the high expectations from doctors, almost all participants expressed having minimal expectations of care from allied health professionals such as pharmacists.

Theme 5: Coping style issues:

'Fatalism', *'depression'* *'self-blaming'* and *'denial'*, all appeared to feed into the coping style of

the participants. A few participants accepted the idea of having asthma because they designated this as “God’s will”. This attitude in a few cases affected self-management routines, where patients believed that they could not do much to treat themselves. A few participants reported mood issues, especially when asthma was coupled with other problems. In some instances, participants felt that it was not important to take care of asthma as they have more pressing issues in their lives to deal with. This led to avoidance of asthma care-seeking from doctors. Some parent participants expressed guilt as they thought their child’s asthma was their fault, which had happened because they had not taken care of their child. Some participants also hinted that they would prefer not knowing the diagnosis or having information would be preferred by them instead of having to live with fear about asthma.

Discussion

This is the first study exploring the perception and experiences of living with asthma in an ethnic group with lower language proficiency in Australia. Despite the high multicultural diversity in Australia, it is surprising that this issue has not been explored previously. As the results indicate, the data produced was thematically rich and loaded with important implications for asthma care. Clearly, these data suggest that there are many issues faced by Arabic-speaking people with asthma with low English proficiency currently living in Australia. These issues include lack of

adequate asthma education and awareness, disengagement in consultations which are culturally or linguistically discordant, and the myriad nature of illness representations or health beliefs.

Data from other multicultural western countries suggest that asthma-related health disparities amongst population groups that constitute an ethnically diverse minority are widening compared to the mainstream population in these countries [27]. Therefore it is important that studies such as the one presented here are conducted to map the potential reasons for such health care gaps in minority populations and target interventions that can improve asthma care.

In our sample, a third (32%) of the participants had good asthma control, a third (32%) had partially controlled asthma and the remainder (36%) had poorly controlled asthma. Davidson *et al.* (2010) highlighted that one of the key concepts relating asthma outcomes to ethnicity includes health literacy [28]. Low health literacy skills have been reported in those with asthma in several multicultural English-speaking countries, such as the United Kingdom, United States and Australia [29]. It has been reported that “cultural factors (i.e. symptom descriptors, distrust and negative health beliefs) may exacerbate or contribute to low health literacy by negatively influencing patient–provider communication” [30]. All of these were evident in our culturally cohesive sample where some patients had lost faith in their physicians and had varying health beliefs that are not concordant with an allopathic or conventional treatment of asthma.

In our sample, there also appeared to be a lack of trust in system-provided facilities, such as translators. Other factors leading to variability in asthma outcomes in our sample could include cultural norms, culturally nuanced illness representations and health beliefs, as well as life experiences, prior experiences with healthcare professionals, religious beliefs, personalities and even events occurring at the time of onset of asthma [30]. These beliefs dictate how people with a common ethnocultural identity may respond to and interact with health care systems and treatments.

It was apparent from the analysis of our data that adherence to asthma medications was low. Health beliefs are a major factor in adherence and cultural variance in health beliefs about asthma and asthma medications have been the subject of other studies [30]. For example, Le et al. (2008) highlighted that African Americans expressed greater fear about steroid side effects than non-African Americans [31]. In another cross-sectional survey conducted in three London hospitals serving highly multicultural communities, all parents accompanying their child to a hospital Accident and Emergency (A&E) department were surveyed. South Asian parents compared to Western parents were more likely to have not given their child asthma preventers from a fear of addiction; they were also likely to hide their child's asthma from others (stigma). Stigma and guilt were also expressed by some of our participants [32]. Similarly, in our study, there were strongly expressed beliefs about side effects, especially of inhaled corticosteroids and

fear of long term use of medications leading to addiction. These, as has been discussed for other ethnocultural populations, lead to patients seeking alternative treatments to cope with the fears or concerns about conventional asthma medication [33, 34]. Fear, stigma, and guilt have been reported by other researchers exploring other ethnic groups, for example, Aboriginal adolescents with asthma in Canada [33, 34]. A few participants in our sample expressed how their spirituality directed how they coped with asthma. Fatalistic attitudes have been observed to leave patients disengaged in self-management and consequently vulnerable [35]. Given these factors are well known, health professionals should be aware of these issues and learn to explore, build upon and integrate these into treatment plans for better adherence.

Patient expectations are also an important contributor to treatment acceptance and adherence. Interestingly, in this study sample participants appeared to have unrealistic and high expectations that were clearly not met by the health care professionals providing asthma care. This is in contrast to other studies, particularly with parents where lower expectations about asthma control are often noticed [36, 37]. In our study, some participants had expected their asthma to be ‘cured’ or there to be no symptoms after treatment, and when their physicians prescribed the same treatment as before, they switched to being non-adherent or trying other alternative therapies. Although, higher expectations are thought to drive regular health seeking and better outcomes, expectations need to be realistic. Both communication issues during the health consult

and low asthma awareness may be contributing to unrealistic expectations in some patients/carers.

Several variables may be posited to have shaped these higher expectations in our sample. One factor may be that of living in an urban environment, which is where all our participants were from, and where, given the easy access to high quality health care, health expectations may be higher [38]. Another factor may be ‘migration’, where participants who migrated from settings with less well-developed asthma management systems, might be expecting a much higher outcome. In this population (Arabic-speakers with LEP), setting real-life expectations about asthma control may be a strategy that can be adopted by healthcare professionals.

Whilst this was an exploratory study our findings highlighted many areas of concern, and it was clear that suitable interventions to address these issues need to be designed specifically for the population examined. A follow-on exercise from this study would be to explore health professionals’ experiences in managing ethnic minorities with low English proficiency (e.g. the Arabic-speaking population) as well as auditing the resources available for such populations with asthma. Culturally specific interventions to reduce asthma morbidity are, however, rare. The OEDIPUS trial set in London General Practices, for South Asian parents of children with asthma, is one example [39]. The intervention targeted healthcare providers (GPs) and aimed at

developing their communications skills as well as focussing on patient education. Post intervention, self-efficacy and asthma quality of life improved in the intervention group compared to the control group [40]. In Australia, Indigenous health care workers have been shown to be beneficial for Indigenous Australians with asthma, albeit in small scale trials and culturally concordant treatments modalities, e.g. using musical instruments such as didgeridoos as part of a breathing exercise regimen [41]. In light of our findings, we propose that such culturally concordant intervention studies are required to focus on other minority asthma patients such as Arabic-speakers with low English proficiency. Extracting from similar findings in the literature, such culturally focused interventions need to focus on: 1. patients and their community (increasing community asthma awareness), 2. health professionals (cultural competence and access enhancement), and 3. developing culturally congruent resource materials. Thus, developing and evaluating such comprehensive programs and interventions are clear directions for the future.

Our study has inherent limitations. All participants were recruited from Melbourne, a metropolitan hub, therefore Arabic-speaking people living in other cities in Australia or indeed in regional/rural areas may have had different perspectives, although we evidenced a saturation of themes in our sample. A maximum variation sample was aimed for, however, all participants were women. In Australian adults, the prevalence of asthma is higher in females than in males. It

is well known in Australian research that male non-participation in research studies is higher than in females [42] and, in our sample, cultural factors may have compounded the unwillingness to participate. We also excluded participants who did not have current/recent asthma symptoms as these participants may not have had recent experience with asthma. However, this may also have excluded those who have well controlled asthma or those that may be in denial of asthma symptoms. Nonetheless, we believe that as one of the few studies on this topic in Australia, the data provided valuable insight into the topic. We also did not use any questionnaires to explore acculturation or health beliefs/medication in this population, although, of course language proficiency may be considered as a proxy for acculturation.

Conclusion

In conclusion, the asthma management experiences of Arabic-speaking Australian with low English Proficiency are varied. There are many treatment gaps, including poor asthma control and non-adherence to treatment, as well as low asthma awareness. A lack of engagement with the healthcare system was evident. Culturally concordant interventions that address such gaps need to be designed and tested, and more research in this area is needed to lower asthma outcome gaps in ethnic minority groups in Australia.

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Conflict of interest

None of the authors declare any conflict of interest.

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Table 2: Demographics details of interview participants

Participants' demographics(n = 25)	Variable details	n (%)
Gender	Female	25 (100)
Age (Years)	20 s	5 (20)
	30 s	7 (28)
	40 s	2 (8)
	50 s	1 (4)
	60 s	5 (20)
	70 s	5 (20)
Length of having Asthma (years)	<5	5 (20)
	5-15	3 (12)
	>15	17 (68)

Family history with Asthma	Yes	18 (72)
	No	7 (28)
”Numbers of years of having lived with asthma”	≥10	17 (68)
	<10	8 (32)
Asthma control*	Good-Control	8 (32)
	Partial-Control	8 (32)
	Poor-Control	9 (36)