SOUTH ASIAN WOMEN'S EXPERIENCE OF MENOPAUSE





South
Yorkshire's
Community

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Executive Summary

This report was commissioned by NHS England and managed by the South Yorkshire Innovation Hub, Diversecity, South Yorkshire ICB, and South Yorkshire's Community Foundation. Working Together in Research is intended to develop better working practises between researchers and local community groups to address embedded health inequalities and services. The research aimed to understand the lived experiences of South Asian women and the impact of menopause on their lives.

Women are not a homogeneous group and experience menopause differently and navigate it differently. The research offers a deeper insight by providing a platform for a marginalised group of women to share their menopause experiences. How menopause symptoms affected their daily lives, work, and family relationships, and the steps they took to improve their health and wellbeing, managing other health and self-care. The strategies they employed to navigate this phase of life, their support systems, and the significance of faith were key topics of discussion.

This report has been split into different sections to reflect the themes that came up during the focus groups.

Coproduction and health care research with global majority women



Coproduction starts with a comprehensive understanding of the health issues faced by women from the global majority. When the community researcher herself is going through the experience and symptoms as a global majority woman, there is not only empathy but also a shared experience. Understanding the cultural and religious dimensions is crucial, as it integrates a significant aspect of women's self-care into the research.

Certain subjects are sensitive and not talked about; a lot of work took place to normalise menopause conversations when the researcher started experiencing symptoms. Before this research, the researcher had advocated for women's health and wellbeing, emphasising the importance of physical activity, embracing a healthy lifestyle, and initiating discussions on a subject that was considered taboo. The lived experience made it easy to discuss menopause in the focus group, as conversations with some of the women had taken place informally before the research on the topic.

The preliminary conversation with the women was guided by the formulation of the questions for the focus group, allowing women to convey their stories. A basis of trust had been built before the research commenced. Not all participants were proficient in English; the researcher spoke the same heritage language, ensuring that every woman could express her experiences, and they were documented accurately. Focus groups were conducted during the day for some women, but also in the evenings, to accommodate working women.

"Vou jed your skinhas change"
HOT FLUSHES
"bfemper kg Tregular with my
peinal"

Duration of Menopause

(including when women realised it started)



The participants had very varied experiences. The women were unsure how long menopause should last. Some recognised that menopause starts earlier for South Asian women. Many participants thought they began menopause in their 40s, but some started in their 30s. They realised they had started menopause when they had hot flushes, night sweats, or their periods stopped. Women mentioned that they did not always know when menopause had started, had confused menopause symptoms with other conditions, and had found out many years later.

Blood tests were not always accurate; some women were told they were going through the perimenopause stage, and others with symptoms were told they were not. Some thought they had been going through perimenopause for around a decade. Some of the women were confused as to when menopause had started because some did not have periods for months or even well over a year, and then the periods had started again. Some of the women had not heard of menopause when they started perimenopause. When they found out what menopause was, it was a shock to the system, as they did not know it existed and was not something talked about.

"It's too hard and I don't feel it's at an end yet. How long does it last?"

"I was 55 years old when my periods stopped, night sweats, when it was really bad, I wanted to leave the house at night and go outside and get fresh air."

"I was putting it down to diabetes for 7-8 years. When I started looking into it, it wasn't."

"When the doctor said I was perimenopausal, I did a bit of googling and I'm none the wiser".

Menopause Symptoms

A number of symptoms were mentioned: brain fog, losing and misplacing things, joint pains and aches, anxiety, feeling thirsty, headaches, dry eyes, heating up, hot flushes, nighttime sweating, others feeling cold, not sleeping, dry skin, hair loss. Low iron and vitamins, low immune system and catching cold easily, Mood swings, getting angry, crying and feeling emotional, insomnia, lack of energy, weak bladder, and virginal dryness. Weight gain and difficulty in losing weight.

"I get really bad nighttime headaches, my brain goes mushy, I can't follow instructions, and cannot carry out tasks properly, it's not going in. My brain feels numb, I can't feel anything, I just don't know where or what I'm doing".

Other health conditions

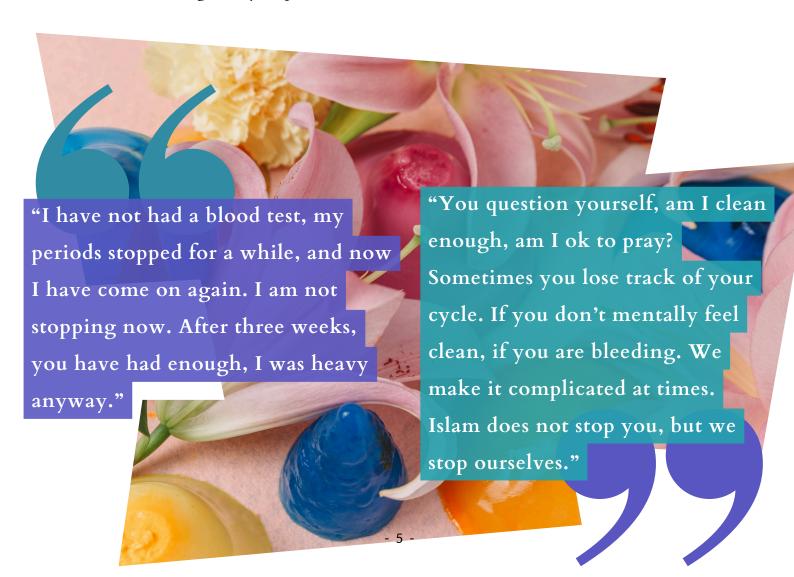
It was hard for the women to know whether their health conditions had been triggered or worsened by menopause or if they were unrelated. Many of the women had diabetes, which had often caused them confusion as to whether symptoms were menopause or diabetes. Diabetes was the most common condition across the focus groups. Some women had osteoporosis, and many had eyesight changes. Other conditions that the women had included fibromyalgia, lupus, arthritis, heart problems, asthma, sleep apnoea, and fibroids. They mentioned that they easily catch colds.

"Since menopause, my immune system has become so weak, I catch things quickly. I sleep like a baby, though. I think the main thing is I think that is why I developed rheumatoid arthritis, osteoporosis, and fibromyalgia. when you hit menopause, you go downhill. Didn't have fibromyalgia before, it's all been after I started menopause at 42. Everything was after."

Menstruation and Bleeding

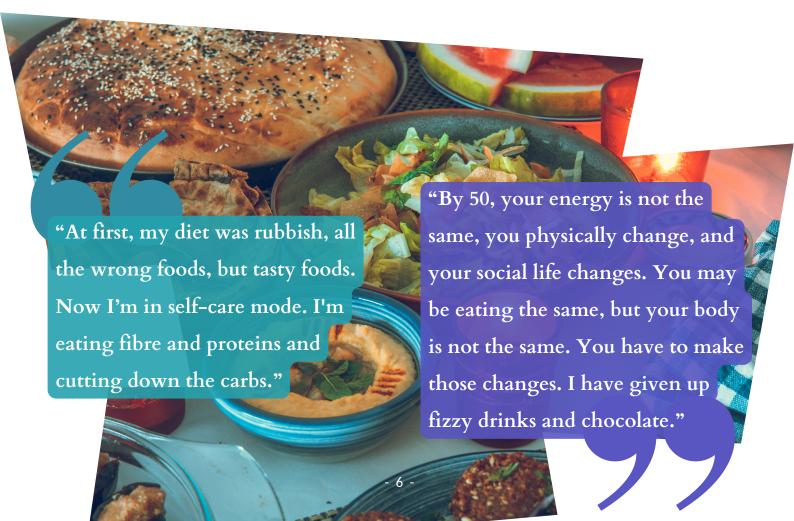


The women spoke about their confusion as to whether their bleeding during menopause is menstruation or other bleeding. They did not know whether and when they could read the Quran. Some said they felt unclean so would never enter the mosque whilst bleeding, but others said they didn't see this bleeding as periods, so would go anyway, or only wait five days. They shared stories of heavy bleeding and how this negatively impacted their lives.



Diet

Women are trying to reduce their carbohydrate and fat intake (especially those who also have diabetes or lupus) and eat more healthily (such as fruit, chia seeds, herbal tea, Greek yoghurt, and vegetables such as okra and spinach). Some have given up fizzy drinks and chocolates. Others have reduced portion sizes, having one biscuit rather than half a pack, walking more, and drinking more water. They were aware of what constituted a healthy diet, but some struggled to stick to a healthy diet. Desi breakfast was an occasional treat. They are not sure whether oil or ghee is healthier. Some women took supplements, iron tablets and vitamins, and herbal teas.







Self Care

Some women mentioned having little time for themselves and only thought about looking after others, such as children, grandchildren, and housework. Others mentioned walking for self-care, such as around the shops or in the park, getting out into the fresh air. They mentioned attending community classes, creative writing, artwork, and crafts as self-care. Some mentioned spending time alone, facials and skin care, and putting oil in their hair, as self-care. Most of them mentioned prayer was a form of self-care. One woman spoke about her work as a form of self-care because she thought it was good for her mental health.

"I tell my daughter-in-law I am having 'me time' and go upstairs and pamper myself."

"Us Pakistani women spend time in the home, looking after the children and husband. They expect us to do this, and that is our job. You get up, clean up, feed the children, we should have some time for our minds."

"I focus on my skin, put mustard oil on my hair, and wash it at night; that is what our mothers used to do".

"The problem is we don't give ourselves enough time. We are the problem; we give time to everyone else. We prioritise our work."

"I need to start doing something, it's not helping me by sitting in front of the fire constantly. A lot of people ask why I'm working. It's not about money; it's about my health."

"I would say take extra care of yourself. Your body is changing,

listen to it. You are going through something."



Reading the holy Quran was very important to the participants and helped them feel strong, calm, and at peace, reciting the Surahs of the holy Quran, Surah Yaseen, Surah ad-Duha, and others, for those who worked, they recited the Holy Quran either first thing in the morning or the evening, they tried to keep up with their 5 daily prayers. Faith helped them with their mental health and well-being, and they found it therapeutic. They felt some of the challenges they faced were part of being a woman, a test, and their faith guided them. One of the participants, who has spoken to young women in the mosque about periods, spoke about how Islam encourages openness around menstruation and menopause. Some found Ramadan easier once their periods had stopped, others had secondary conditions (such as a weak bladder) which made Ramadan more difficult. They had different views about praying and perimenopause, such as when in their cycle they could pray.

"Islam says we must be open and teach them. Our parents weren't educated and learnt only from their parents. Older girls, I talk to them about periods in the mosque. It can't be taboo. Islam is supposed to be very open."

"If we look at Islam, what we are going through elevates our positions. When a woman becomes a mother, she is elevated 3 times higher than the father, "heaven lies at the feet of the mother".

"When you are feeling low and feeling down for no reason, when you turn to your faith, it all disappears. You get support from reading your namaz. All people are different, but turning to faith is a good thing. You can talk to friends, but but they are only with you for five or ten minutes. It helps to bring faith into it. It gives strength to women. Through faith, you find your strength. I feel God supported me through the menopause."

"I read my Quran. I wake up, have a shower, and read my namaz, read Surah Yaseen before I get my breakfast, and go to work. Sometimes I get to do my prayer at school. I read straight away when I get home. Later in the evening, even if I'm doing other things, I read like Surah Rahman. It's soothing, calming, and stops me from overthinking. I think it helps me a lot."



Menopause had impacted participants' family relationships in various ways. Some spoke to a range of family members about menopause, and others did not speak to any. Some women spoke to their sisters, mothers, and nieces about menopause. Others shared how their daughters were supportive, such as taking them out shopping or for food when they felt low. They spoke about generational differences, such as the fact that their mothers never discussed menopause with them and did not share that they were pregnant, but that they would talk to their daughters about menopause now. They said that grandchildren could be difficult to spend time with, because they make a lot of noise. They said that men in South Asian communities were not very understanding of menopause, especially in their generation. Very few spoke to their husbands or sons about menopause because they did not think they would understand. Two women mentioned that they had supportive husbands. One of the participants shared a YouTube video in Urdu about menopause with her husband, and after he watched it, he started supporting her. Another woman praised her husband for his support. For women who did not work, they felt guilty asking husbands for money to pay things like vitamins.

"I think there should be sessions for men so they can be more supportive, they don't understand and don't listen, they make you feel worse than you are. Husbands should be more supportive and understand that their wife is going through it; they should know."

"My family listens but doesn't respond to it, they are aware now. My boys just put their heads down when I talk about it."

"It is sad, you share everything with your partner. You would think this guy would understand after all these years, but he doesn't have a clue. They don't go through it, more sessions for men. There should be some training so men can be supportive of their wives."

"My daughter is supportive; she works for 111 and has information. When I feel low and I get tears in her eyes, she just comes around and says Let's go to Meadowhall, let me take you to Nando's, and you feel that someone understands. It makes me feel like "thank God one of my daughters understands how I feel."

"I forget about yourself, I did, I didn't care how I looked or felt. It was kids, kids, kids, and housework."

"My husband understands now. He thought I was losing the plot. I got a YouTube video in Urdu and sent it to him. I made him sit down and watch it."

"We have boundaries, my mum doesn't like me openly talking about menopause to my daughter, we are friendly. My mum says "Sharam karo"



For the women who worked, the workplace was an important place for breaking down the stigma. Some of the women worked in a more female environment, and some of their female colleagues who were going through menopause gained the confidence to talk about menopause from speaking to colleagues who were not South Asian. They mentioned their white colleagues were more open about it, such as mentioning hot flushes and having a comfortable working environment.

"At the moment, they have changed the heating, my manager is cold, and I am having hot flushes and can't cope with the heating on. She switched it off for a day, and today she's put it back on. I'm going round opening all the windows".

"Only learnt what I had read and people at work talked about it. I work in a school, and we are all women. We all just talk, and we have a lovely relationship. We were always asking one another. In summer, we had fans on, one minute we were hot and one minute cold. Talking about it constantly is great."

"Younger girls are talking about menopause at work, early 30's. I tell them I'm going through menopause, so they understand, they are not going through it yet, but we are preparing them by telling them".

Non-medical treatments for menopause

In general, women preferred herbal and other remedies over medicine. Magnesium, iron tablets, and vitamin D were taken by many of the women. Many drank herbal teas. They also used certain spices in water or in cooking to help with their symptoms (such as turmeric and black pepper). They used oils on their hair and bodies, such as black seed oil and rosemary oil. They also ate seeds, such as fenugreek, chai, ajwain, and carob seeds, to help with symptoms. Women spoke about how certain menopause products, such as caffeine shampoo for hair loss, were out of their budgets. Those who did not work relied on their husbands for money and felt that they could not ask their husbands to pay for any products that would help with the menopause. They spoke about using miswak to clean their teeth because it whitens and strengthens them. During one of the focus groups, the women created a WhatsApp group so they could take photos of the products on the table. Some put collagen in tea. Some had learned about menopause products from TikTok. A few also used hot water bottles and electric blankets to help with aches and pains.

"For my teeth, I use the bark of a walnut tree to clean and whiten teeth. Miswak is a long stick, a natural thing for teeth."

"Turmeric and black pepper are so good for women."

"Rosemary oil is good for your hair. In the Quran, the Prophet Muhammad said Black seed oil will cure all ailments apart from death; every cure is in black seed oil."

"Our religion says give some money to ladies for housekeeping, but don't get extra to be able to justify buying expensive shampoo."

"If you soak fenugreek seeds in water overnight and then wash your hair, mix some shampoo, and it will make it grow and give you thicker hair."

Knowledge, education and awareness

(prior to menopause, during menopause, and beyond)



Many of the women had little awareness of menopause before starting perimenopause. They had gained their knowledge after they started perimenopause, such as by asking their family. They explained that a lot of women in their communities know very little about menopause. Prior to their entering perimenopause, many did not know the words for menopause, either in English or Urdu. Many did not recognise when their mothers were going through menopause and wished they had treated their mothers with more kindness. Only one of the women had learned about menopause briefly in school. They said that women today speak more openly about menopause than in the past. For the women, knowledge is power, and they were keen to learn as much as they could about menopause.

"So many women have approached me, and I feel proud that we have that knowledge to share with others. I personally have helped 3 people in my family. I feel good. It is Sadaqa."

"I didn't know anything at all, I never went to the doctors and never got diagnosed with anything, no support, and thought it was just me going mad."

"I remember back in the days when my mum had these things, I'm thinking this is what she was going through. In winter, she had the window open, and my dad complained that she was freezing him. 30 years ago, this was nothing to no one, and now everyone knows what menopause is."

"No, I thought I was losing the plot. No, I did not know I had gained a lot of knowledge, so I know what to expect, so I know what I am going to do."

"My sisters are educating their own daughters. They are getting their daughters ready from period to menopause."

"A lot of people in our community don't know about it."

"The Urdu word is Mahwai, sometimes Sunyas - same meaning".

Interaction with Medical Professionals

(such as medical appointments)



They had a range of experiences with doctors. Some spoke to a GP as their first port of call, others had never spoken to a GP about menopause. Some were convinced they had started perimenopause, but the GP said they had not. One participant was surprised to be told she had started perimenopause. They shared their struggles to advocate for themselves so that they could receive a diagnosis and the right treatment. Some spoke about being dismissed by GPs and GP surgeries. Others mentioned that they were prescribed antidepressants, but this was not what they felt was best for them. GPs could not always tell whether symptoms were menopause or another underlying condition. Some mentioned relying on Google for information rather than a GP.

"Why am I suffering so much, and why is no one helping me? I struggle to advocate for myself, my sister says I'm too nice. I try to explain, but unless you are screaming and shouting, they don't listen. I put a stone on. You don't feel confident, you look in the mirror and you think of someone else, the best way to describe it is imposter syndrome."

"I never went to the doctors and never got diagnosed with anything, no support, and thought it was just me going mad."

"I had to argue and fight for them to do blood tests. My oestrogen was low. I went on HRT, but I didn't react very well to it. The doctors didn't seem to know what to do next. It was like Here's your HRT patch, but it's not working. they don't follow tests, don't do bloods, check your levels, nothing changes. I had to go private."

"GPs do tend to fob me off. It is hard to get appointments and get past receptionists."

"I go to my doctors and come home, and Google and my GP told me not to Google everything, who says everything on the internet is accurate. I didn't want HRT as I'm scared, but she asked me why I was listening to other people and not trying it."

"Doctors need to be more educated about menopause."



Very few of the women in the focus groups had ever taken any medication for menopause. Many spoke about avoiding medication where possible. Most of the women refused to try HRT because they had heard about negative experiences from family and friends (such as causing severe depression). They were therefore too scared to try it. Very few had tried HRT, and most that had have now stopped. One mentioned not being booked in for follow-up appointments and then coming off HRT. One woman used a spray but was concerned that she was not using it properly. Some had been given antidepressants, but they were not sure why.

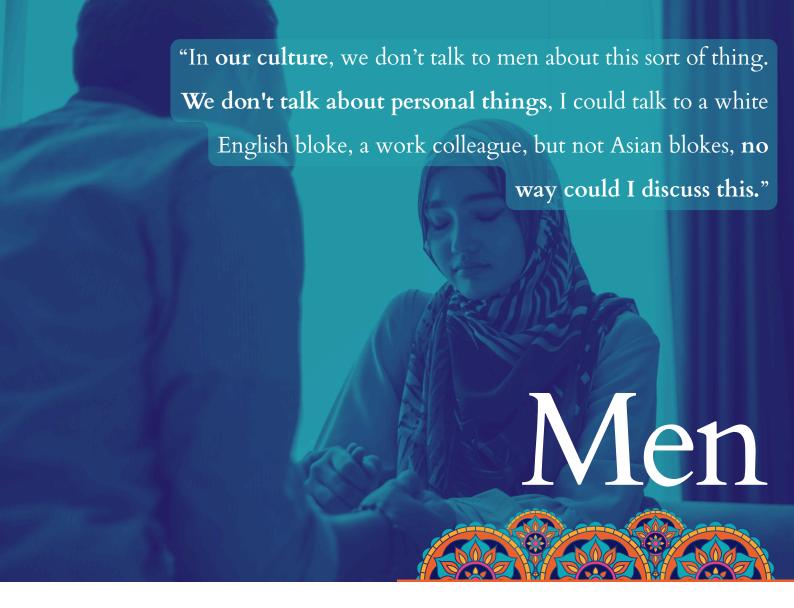
"I came off HRT when I was given it, and I used willpower, did some walking and exercise, getting out and doing something, I kept busy and mentally you are busy."

"I try to avoid medication as much as possible. My daughters take paracetamol, but I won't take it for a headache, I put up with it and don't take it."

"I have been offered HRT, and I haven't taken it as advised, it can make you go mental, loopy, and suicidal. One of the ladies I work with said, Don't take HRT, it made her woppy and suicidal, I said no to the doctor".

"I didn't want HRT as I'm scared, but my GP asked me why I was listening to other people and not trying it."

"I started HRT thinking it would help, but it didn't. I went back to the doctors, and they put me on antidepressants, but this settled it a little."



The women talked about how men in their communities did not understand their menopause experiences. They said that men should be educated about menopause in school and trained about it at work. Some women mentioned that they are more comfortable talking about menopause to English men (such as a boss) than men in their communities.

"I think there should be sessions for men so they can be more supportive, they don't understand and don't listen, they make you feel worse than you are."

"I can talk to a white boss about it, it's to do with culture and the way Asian men are brought up."

Social media and the internet



Some women mentioned using Google to find out about menopause and menopause symptoms. Quite a few of the women had learned about menopause and bought products from TikTok because they had been advertised as good for menopause symptoms (this includes apple cider vinegar). Some had learned about the menopause from a social media influencer and professionals like Dr. Nighat Arif.

"I respect Dr Niggat, you learn something new."

"I used to go on TikTok, and they were talking about symptoms. Lots of English ladies talk about this. You get professionals also on TikTok."

"I believe Google comes in here because doctors don't want to tell you about it."

Stigma, Taboo, and Embarrassment



The women mentioned that menopause and menstruation were stigmatised and taboo topics that were very rarely mentioned in their communities. They said that these topics can be embarrassing to discuss and that their mothers' generation did not speak about these topics whatsoever.

"It's cultural. It's something that we don't hear about."

"Menopause is a problem we women are facing, but we struggle to talk about, and we do not cope with it."

"I talk to my mum; she is my pal. Not sure what the word is for menopause in our language."



The woman stated that just talking to someone helped. Some mentioned going to women's groups or health sessions where menopause is discussed now, and information is given. Some of the women mentioned receiving support from other women who have or were going through it, which reassured them that they were not alone. They were becoming more aware of the symptoms and said menopause conversations were needed.

"We have done a lot of courses, and we haven't stopped since. We like to know. This is my 10th session attending, so when I talk about it, I have been to lots of sessions".

"Talk, share, go to doctors, go to a professional, community nurses out there, see your nurse, talk to someone, and get it out. Reassure them it's normal and you've been through it."

"Should have something like this. I now feel that I'm not the only one, and I'm not going crazy. We should have more conversations. Menopause conversation is needed. Menopause cafes, when you are working, you cannot get to them, on weekends and evenings."

Recommendations



- More information should be provided by medical practitioners on the use of HRT so women can make an informed decision.
- Blood tests as standard for women over 40 who are experiencing menopausal symptoms. They start their menopause so much earlier than White British women.
- More **support for working women** who struggle at work, they should be supported to remain in work.
- A specific support group or menopause café for women from the global majority where they can get information and advice, including cultural and religious.
- Training for organisations and workers from the global majority who work with women from their community, so that isolated women are not excluded.
- More documentation aimed at men, so they can at least learn about Menopause and how to support their wives, mothers and sisters.
- Information placed in GP surgeries that is **easily accessible for everyone**, help remove the stigma of women having to ask.



Ajwain (carom seeds) - is a spice with a distinct flavour and diverse health benefits. They are a good source of fibre, iron, and magnesium, which helps to improve digestion, reduce inflammation, and lower cholesterol.

Carob- a flowering evergreen tree or shrub in the Caesalpinioideae sub-family of the legume family, Fabaceae. It prevents infection, helps digestion, supports cardiovascular health, and strengthens bones.

Chia seeds- are the edible seeds of Salvia hispanica, a flowering plant in the mint family, containing fibre, protein, omega-3 fatty acids, and antioxidants.

Fenugreek- is a plant with seeds and leaves used in cooking, and helps with inflammation, cholesterol, and blood sugar.

Miswak – a traditional chewing stick prepared from the roots, twigs, and stems of Salvadora persica and has been used as a natural method for tooth cleaning in many parts of the world for thousands of years.

Sadaqah- in Islam, refers to voluntary acts of charity or generosity, given with the sincere intention of pleasing God and benefiting others. It can range from monetary donations to acts of kindness, compassion, and service. Sadaqah is a key aspect of Islamic faith, emphasising the importance of helping those in need and fostering a charitable society.

Sharam karo- translates to "Have some shame."

Surah Al Rahman- emphasises the merciful nature of Allah, who has created everything in the universe with wisdom and purpose

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