

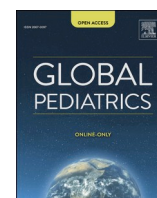
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Health professionals and women's knowledge and experiences of caring for small gestational age (SGA) infants in Pakistan

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ABSTRACT

Background: In Pakistan, every third baby is born small for gestational age (SGA). Early antenatal detection of SGA helps with birth planning and initial treatment of mother and baby, thereby reducing complications. Screening and diagnosis of SGA however are challenging, especially in low and middle-income countries where access to technological advances may be limited and there is a lack of routine antenatal screening.

Aims: To explore the current practices, knowledge, and experiences of caring for SGA infants with women and health professionals in Pakistan.

Design: A cross-sectional survey with healthcare professionals and focus groups or interviews with health professionals and mothers of SGA babies were undertaken. Survey data were analysed descriptively and integrated with the qualitative data using thematic data analysis.

Subjects: 78 completed surveys were returned and eight FGDs and five interviews were undertaken with 77 participants – 67 healthcare professionals (gynecologists/obstetricians, neonatologists, Lady Health Workers, and Lady Health Visitors) and 10 mothers of SGA infants aged under 12 months.

Results: The survey highlighted a general lack of training on SGA for all health care professionals, but particularly amongst community staff who often act as primary caregivers for women. Five qualitative themes described the challenges and issues faced in the management, treatment, and prevention of SGA in Pakistan: Lack of policies and training, Lack of resources, Lack of access to healthcare, Not following the guidance, and Lack of data and reporting.

Conclusions: A whole system approach to improve service provision and outcomes is needed. This should include epidemiological research, country-specific policies, training for healthcare professionals and awareness raising amongst women and community members.

Introduction

Infants born small for gestational age (SGA) are defined as those weighing below the 10th centile of birth weight by sex for a specific completed gestational age of a given reference population.¹ Infants born SGA may be either constitutionally small and physiologically normal or as a result of fetal growth restriction.² Infants born SGA due to fetal growth restriction carry an increased risk of adverse birth outcomes, poor growth, impaired cognitive development, and a higher risk of chronic disease in later life. These morbidities in turn place them at higher risk of death extending beyond the neonatal period and the risk is

exacerbated in those infants born both preterm and SGA.³ Modifiable risk factors for SGA include poor maternal nutrition,⁴ maternal infections and other morbidities,⁵ young maternal age,⁶ and short birth spacing.⁶

Approximately 32 million infants are born SGA in low and middle-income countries (LMIC) (27 % of live births).⁷ The highest burden of SGA is concentrated in South Asia; in Pakistan every third baby is born SGA, accounting for 26 % of all neonatal mortalities.⁷ It has been estimated that if the prevalence of SGA was reduced to a level of 10 % in all LMICs, an estimated 9.2 % of all neonatal deaths could be averted.⁷ Observational studies suggest that improved antenatal detection of SGA

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babies may half the stillbirth rate⁸ and early detection helps in planning delivery and initial treatment.⁹ Screening and diagnosis of SGA are challenging, especially in LMIC countries where access to technological advances may be limited and there is a lack of routine antenatal screening. Several diagnostic tools and risk assessment methods such as clinical assessment, biochemical analysis, laboratory services and ultrasonography may be available to identify the risk of adverse pregnancy outcomes in specialized care hospitals; but only a limited proportion of the population has access to these services. Similarly, interventions that improve the care and survival of infants born SGA, e.g., early feeding support, kangaroo mother care, early detection and treatment of neonatal infections, and neonatal resuscitation, often do not reach the settings of greatest need.^{7,10} Studies conducted in Pakistan have highlighted the need for improved guidelines and management of SGA births together with periodic evaluation.¹¹

This study aims to explore the current practices, knowledge, and experiences of caring for SGA infants with women and health professionals in Pakistan. Our study objectives were to: (a) explore the practices and experiences of health professionals relating to the identification and management of SGA; (b) explore mothers' knowledge and experiences of having a baby born SGA; and (c) conduct a cross-sectional survey to identify the range and types of service provision and policies relating to the identification and management of SGA babies and their mothers.

Methods

Design

An exploratory design using surveys and qualitative methods aimed to elucidate the current practices, knowledge and experiences of women and health professionals about SGA in Pakistan.

Participant recruitment

The data was collected in three stages:

1. A cross-sectional survey was developed and piloted before being distributed amongst health professionals throughout four provinces (Punjab, Khyber Pakhtunkhwa (KPK), Sindh, Balochistan) and one federal territory (Islamabad Capital Territory) of Pakistan to explore the range and types of service provision and policies relating to the prevention, identification and management of SGA babies and their mothers. Trained research assistants conducted telephone surveys to support online data collection. The surveys were distributed via WhatsApp groups and personal contacts.
2. Five focus group discussions (FGDs) were conducted with health professionals and mothers of SGA babies living in Peshawar, Khyber Pakhtunkhwa. Health professional participants were recruited from three tertiary care hospitals in the Peshawar district. Two FGDs were conducted with gynecologists/obstetricians and one FGD was undertaken with neonatologists. Three FGDs were undertaken with women only, Lady Health Workers (LHW) and women, or LHWs and Lady Health Visitors (LHVs). Research assistants met with the Head of Gynecology departments at each hospital and explained the purpose of the study and provided information sheets. The Heads were asked to disseminate the information amongst the relevant staff in their departments. Participants were eligible to participate if they had at least 3 years of experience working in the gynecology department of the hospital. Mothers of SGA infants were identified by hospital staff from hospital records. Mothers were eligible to take part if they lived near the Basic Health Unit, on the periphery of Peshawar and had an infant aged up to 12 months who had been identified as SGA. Those with preterm infants were excluded. The topic guide was piloted with a small group of participants and minor

changes made as appropriate. None of the participants who were contacted refused to take part or dropped out of the study.

3. A further three FGDs were undertaken in KPK, and 5 interviews were conducted with gynecologists/obstetricians across four provinces (KPK, Baluchistan, Sindh and Punjab) and federal territory (Islamabad, Capital). Participants were recruited via WhatsApp groups and personal contacts and none who were contacted refused to participate or dropped out of the study.

All participants were given a participant information sheet (PIS), translated into the local language, to read and consider before consent was obtained. Research assistants were available to answer any questions about the PIS and/or read it to illiterate mothers. Low-value rewards for participation (i.e., gift hampers containing food or grocery items) were given to the women who participated in this study.

An email, information sheet and consent form were forwarded (electronically), and participants were asked to respond within two weeks if they would like to take part. The interviews were held via telephone or online (via Teams) as preferred. At the start of data collection, the consent statements were read by the researcher with the participant asked to provide verbal agreement to each and to record their name and date. The consent recording was stopped and stored separately from the interview recording. For online interviews, participants were asked if they wished to be audio and/or video recorded. The FGDs were held face-to-face, and participants were asked to review and sign a consent form. If mothers were illiterate, they were asked to give consent by marking initials or an X on the consent form, witnessed by an independent, literate adult who was not part of the research team.

Data collection

A cross-sectional survey using the Qualtrics platform was undertaken to explore the range and types of service provision and policies relating to the prevention, identification and management of SGA babies and their mothers across Pakistan. We collected information on the type and size of the hospital (e.g., public or private), the existence of relevant policies, details of prenatal care and antenatal follow-up for babies born SGA and whether any training had been provided.

FGDs were conducted by two research assistants from Khyber Medical University, fluent in both English and the local languages; Urdu and Pashto. The research assistants were experienced in qualitative methods and received additional training from an experienced qualitative researcher (UM). FGDs were conducted in convenient locations for the participants (i.e., in the health professional's hospital and the Basic Health Unit in the periphery of Peshawar for mothers). FGDs and interviews with neonatologists and gynecologists/obstetricians were conducted in English, and FGDs with LHWs, LHVs and mothers were conducted in Pashto.

Topic guides, created by co-authors who have expertise in maternal and neonatal health (UM, SF, VHM), were used to guide the discussions. Health professionals were asked about their knowledge, current practices, and workplace policies on the management and treatment of SGA infants and their mothers. Mothers were asked about their knowledge and experiences of having an SGA infant and sought to understand where they obtained their information and support.

Interviews and FGDs were audio recorded using a passcode-protected device or via online functionality, transcribed by research staff and then translated into English as appropriate. The original recordings were then deleted from the encrypted Dictaphones within one day of the FGD. All data collection took place between September 2020 and July 2022. Interviews lasted between 35 and 45 min and FGDs between 60 and 90 min.

Reflexivity

This study was undertaken by a team of researchers based in the UK (VHM, GT) and Pakistan (SF, SHH, UM, RN). The team involved

individuals from nutrition (VHM, SF), psychology (GT), gynecology (RN, SF), physiology (SHH), and public health and health profession education (UM, SF). None of the team members have provided clinical care for the treatment and management of SGA. All research team members approached this study with an open mind to the challenges faced, and a commitment to improving care practices and outcomes. Project team discussions (VHM, GT, SF, UM, SHH) were held to review data quality and to ensure that final interpretations represented the whole data set.

Analysis

Survey data were analysed descriptively using SPSS. Audio recordings of the FGDs and interviews with lady health visitors and mothers were transcribed and translated into English. FGD facilitators double-checked all the transcripts for accuracy. All participant names or identifying information were removed to maintain participant anonymity. Qualitative data were coded and thematically analysed concurrently by researchers, both in the UK (GT, VHM) and Pakistan (UM) using MAXQDA (www.maxqda.com/) and Atlas.ti qualitative data analysis software, respectively. Thematic data analysis was undertaken using the six-step reflexive thematic analysis proposed by Braun and Clarke.¹² We used the consolidated criteria for reporting qualitative studies (COREQ) in the reporting of our results.

The first two and fifth authors independently familiarised themselves with the data, generated initial codes, searched for themes, and defined and named initial themes. Candidate themes and interpretations were presented to the wider team with any changes made through discussion and feedback until consensual validation was achieved. Once themes had been agreed upon, descriptive data from the survey were integrated to substantiate the findings generated (where appropriate).

Table 1
Survey responses.

Type of hospital	Public	Private	Both public & private
N	50 (64.1 %)	24 (30.8 %)	4 (5.1 %)
Births per year	1500–50,000	500–2000	Not answered
Is there a neonatal unit at the hospital?	37 (74.0 %)	17 (70.8 %)	4 (100 %)
Are you aware of any policies or guidelines for the screening of women for SGA?	Yes 27 (54.0 %) No 17 (34.0 %) Not reported 6 (12.0 %)	Yes 8 (33.3 %) No 13 (54.2 %) Not reported 3 (12.5 %)	Yes 4 (100 %)
Are you aware of any policies or guidelines for the treatment of women and their infants who are born SGA in your hospital?	Yes 24 (48.0 %) No 19 (38.0 %) Not reported 7 (14.0 %)	Yes 8 (33.3 %) No 12 (50.0 %) Not reported 4 (16.7 %)	Yes 4 (100 %)
Are you aware of any policies or guidelines to prevent women from having an infant born SGA?	Yes 29 (58.0 %) No 14 (28.0 %) Not reported 7 (14.0 %)	Yes 7 (29.2 %) No 12 (50.0 %) Not reported 5 (20.8 %)	Yes 3 (75.0 %) No 1 (25.0 %)
Do you think the policies and guidelines that are in place in your hospital are sufficient and appropriate for the care and management of women suspected/of having an SGA baby?	Yes 16 (32.0 %) No 28 (56.0 %) Not reported 6 (12.0 %)	Yes 10 (41.7 %) No 9 (37.5 %) Not reported 5 (20.8 %)	Yes 4 (100 %)
Do women receive any information or advice regarding the prevention of SGA?	Yes 19 (38.0 %) No 17 (34.0 %) Not reported 14 (28.0 %)	Yes 12 (50.0 %) No 4 (16.7 %) Not reported 8 (32.3 %)	Yes 3 (75.0 %) No 1 (25.0 %)
Do women have a formal assessment of their risk of delivering an SGA neonate?	Yes 16 (32.0 %) No 20 (40.0 %) Not reported 14 (28.0 %)	Yes 12 (50.0 %) No 2 (8.3 %) Not reported 8 (33.3 %)	Yes 3 (75.0 %) No 1 (25.0 %)
Are women who have a major risk factor for an SGA neonate offered serial ultrasound measurement of fetal size and assessment of well-being?	Yes 17 (34.0 %) No 4 (8.0 %) Not reported 29 (58.0 %)	Yes 15 (62.5 %) No 2 (8.3 %) Not reported 7 (29.2 %)	Yes 4 (100 %)
Have you received any training on the identification and management of SGA?	Yes 10 (20.0 %) No 24 (48.0 %) Not reported 16 (32.0 %)	Yes 3 (12.5 %) No 3 (12.5 %) Not reported 18 (75.0 %)	Yes 2 (50.0 %) No 2 (50.0 %)

Ethical considerations

Literate participants were given a Participant Information Sheet (in Urdu) and asked to give their consent. Study information was read to participants who were not literate, and they indicated their consent by signing with their initials or an X. The study participants were allotted identity numbers during the selection process to keep their identity anonymised. Participants were informed of their rights to participate and that they could withdraw from the study at any time. This study was reviewed and approved by research ethics committees at the University of Central Lancashire in the UK (reference HEALTH 0018) and Khyber Medical University in Pakistan (reference KMU/2020/18).

Results

Overall, a total of 77 participants took part in FGDs or interviews. This included 42 gynecologists/obstetricians, seven neonatologists, 18 LHWs and LHV, and 10 mothers of SGA infants aged under 12 months.

Seventy-eight surveys were completed by assistant/associate professors ($n = 7$), professors ($n = 2$), doctors/consultants ($n = 24$), medical officers (including trainees and women medical officers) ($n = 36$), pharmacists ($n = 1$), nurses ($n = 1$), clinical researchers ($n = 3$) and one did not report their profession. Participants were mainly from public hospitals ($n = 50$), with the remaining working at private hospitals ($n = 24$) or private and public hospitals ($n = 4$) (one did not provide this information). The number of births in public hospitals ranged from 1500 to 50,000 and in private hospitals from 500 to 2000. An overview of answers to the survey questions, according to the type of hospital is presented in [Table 1](#).

Our qualitative work identified five themes that depicted the challenges and issues faced in the management, treatment, and prevention of

SGA in Pakistan. This will be described, together with illustrative quotes, alongside the survey data.

Lack of policies and training

Survey findings revealed that around 50 % of health professionals had some awareness of the availability of policies or guidelines to screen, prevent or treat SGA, although many (47 %) thought that the guidelines that were in place in their hospitals were insufficient. While some participants referred to following UK guidelines (such as RCOG or NICE), others commented on how they were not routinely implemented:

Basically, we follow the guidelines of RCOG and NICE. We provide the NICE guidelines to our trainees. We use these guidelines where we need it but it's not 100 % (FGD6_Gynecologists/Obstetricians)

Many of the participants referred to how the availability of local guidelines was lacking: 'we don't have any policies for SGA' (FGD4_Gynecologists/Obstetricians).

Some reflected on how a lack of consistency in terms of availability and/or use of the guidelines meant that there were *'individual disparities in the approach to assessing the patient'* (Interview 1_Gynecologist/Obstetrician). A further participant reported:

There are no exact and proper strategies. But if you have knowledge, we just apply our knowledge. We are supposed to have a strategy for it [SGA]. But unfortunately, we don't (Interview 3_Gynecologist/Obstetrician)

A further issue related to training for healthcare staff, and while non-reporting was high for this survey question, only 19 % reported receiving any training on the identification and management of SGA. While participants in one of the FGDs, reported on how they provided training on *'how to prevent, diagnose and manage SGA'* (FGD8_Gynecologists/Obstetricians), participants in the other groups stated they had *'never attended special training on SGA'* (FGD6_Gynecologists/Obstetricians), with a lack of training for gynecologists perceived to be an *'important factor'* (FGD8_Gynecologists/Obstetricians). Participants were also critical of the lack of training and supervision given to midwives, LHWs and LHVs. This was felt to be particularly pertinent when, as one participant explained, *'34 % of our women are delivering outside the hospital still. And 24 % by traditional birth attendants not even trained'* (Interview 5_Gynecologist/Obstetrician). A further participant stated:

One thing that I want to add is LHWs training. The problem starts from there they recruit matriculate girls and gave them low-quality training for 18 months. Now they are in communities and the surrounding people are considering them as a doctor. And the patients only trust them. As they are available 24 h. This is basically a failure of policies and a lack of education. The government has given the authority to LHWs that they can treat any type of patient, they have no follow-up, no verification, and no supervision. They are free to do anything with patients. When we want to do something for the patient and counsel the patients regarding their pregnancy, they immediately visit their periphery doctors and they consider their suggestions more valuable and follow them, finally, they end up with complications. And finally, we have to deal with complications. (FGD7_Gynecologists/Obstetricians)

The lack of awareness amongst this professional group was also acknowledged by LHWs themselves: *'We don't have any skill and knowledge in relation to SGA. We want that there should be seminars and workshops regarding small babies'*. (FGD1_Mothers & LHWs)

Lack of resources

A key problem regarding the screening and management of SGA was reported to be related to a lack of suitable care. From the survey responses, only 40 % of participants reported that women have a formal

assessment of their risk of delivering an SGA baby, and 46 % stated that they offered best practices (i.e., serial ultrasound, assessment of well-being) to those identified as high risk. Inadequate care was attributed to large workloads, insufficient staffing, a lack of time, and a lack of facilities and resources:

The important thing is that the workload is very high. Per day we must check 120–160 or more patients. The patients are not organized and triaged. High-risk patients deserve more time. In high risk, 60–70 % of patients get ignored/missed just because of overload. We can organize and prioritize the patients but due to lack of staff, we cannot do this. (Interview 1_Gynecologist/Obstetrician)

Health professionals also highlighted the lack of postnatal follow-up, even after cesarean section, with mothers being discharged soon after birth. Participants referred to how this often resulted in doctors being unaware of whether the baby they cared for at birth survived unless they met the mother again during a subsequent pregnancy:

There is no proper follow-up of babies born with fetal distress, pre-term labor and placental abruption. Mother wants to go home just after the baby is delivered. So, we don't know what happened to the baby in the next few days or what was the neonatal outcome until the mother came up with another pregnancy and tells us about the previous baby, that the baby is alive or may have died within a few days of life. (FGD4_Gynecologists/Obstetricians)

Health professionals often reported that their hospital was *'unable to provide all the facilities'* (Interview 2_Gynecologist/Obstetrician). Access to appropriate care was impeded by the lack of vital resources and equipment, such as Doppler ultrasounds, which may restrict accurate and timely diagnosis and subsequent treatment. One health professional commented, *'By the time we diagnose SGA, it may have become an IUD (intrauterine death), or it may have already been missed, or it may be at a critical stage'* (FGD7_Gynecologists/Obstetricians). When such equipment was unavailable at their hospital, health professionals may refer the mother to private care, although it was acknowledged that *'for most of the families Doppler ultrasounds are not affordable'* (Interview 5_Gynecologist/Obstetrician).

Hospitals often lacked specialist services with only 74 % of survey respondents stating that there was a neonatal unit in their hospital to care for SGA infants. Specialist staff, such as neonatologists and nutritionists to treat babies born SGA, were also felt to be lacking. Some participants also referred to the lack of coordination and management both within their hospital and between health care services:

I think many patients come for follow-up, but they land up in some other unit. So, this is a big problem in our hospital that we have no management and coordination among all gynae units. We are running the gynae department on three floors. So as a consultant, we don't have specific days throughout the year whether we will be available in the hospital or not. Patients only come on their own choice and the specific doctor may not be available at that time. So many patients land with some other doctor in the same or different unit. (FGD6_Gynecologists/Obstetricians)

Lack of access to healthcare

The inadequate care reported above was also reported to be exacerbated by a lack of antenatal and postnatal care engagement by mothers. Some of the mothers involved in this study referred to attending regular check-ups, *'I did all my blood tests and ultrasound; thanks to God everything is fine'* (FGD1_Mothers & LHWs). However, professionals frequently recounted how women will often only attend infrequently, *'they don't make it more than 3 and 4 visits'*, and some would only attend when they experience complications (but not necessarily so), or at the point of delivery:

Mothers only visit tertiary care if they have some critical issues otherwise, they don't even come for their regular checkups. They only come at the time of delivery. (FGD4_Gynaecologists)

Late attendance also created difficulties in terms of what care could be provided:

The patient comes in the second trimester or even after that. So, at that time, there is no role of prophylactic measures after the initiation of SGA which has already started, and we just have to go for serial growth monitoring. (Interview 1_Gynecologist/Obstetrician)

One participant referred to how they would *'tell them strictly to come for follow-up'* if complications had been identified and perceived this to be a helpful strategy as *'in this case, they try their best to come on time'* (Interview 2_Gynecologist/Obstetrician). Although from a mother's perspective, there were complaints about being unaware that there may be a problem with their baby's size:

When my baby was delivered at the hospital, I came to know that my baby is very small than normal. Doctors never told me that your baby will be born small. (FGD3_Mothers)

One participant also highlighted how parents receive no information on *'why their baby dies'* (FGD4_Gynecologists/Obstetricians).

A lack of postnatal attendance was also noted. There were also occasions reported of women attending for postnatal follow-up but leaving their babies at home. This lack of contact meant that the effectiveness of strategies to treat SGA was impossible to determine:

The effectiveness of strategies can only be found out by the feedback of patients. But very few patients come for follow-up after delivery. (FGD6_Gynecologists/Obstetricians)

A lack of access was also confirmed by women, with one reporting, *'I never did my proper checkup as we have no one to take us to the hospital'* (FGD3_Mothers). While this quote indicates difficulties in organizing transportation, distance from home to health facilities (and often about tertiary care), coupled with poverty, was believed to create insurmountable challenges: *'But the malnourished poor population is living in villages and has no approach to tertiary care hospitals'* (FGD4_Gynecologists/Obstetricians). In one of the interviews, women who were being referred for specialist treatment were reported to refuse as they could not *'afford to travel'* (Interview 1_Gynecologist/Obstetrician) or to pay for their care. One of the mothers also stated:

We can manage our health condition up to some extent but in our community, families can't afford hospital charges. (FGD1_Mothers & LHWs)

The attitudes of others could also influence women's willingness to attend antenatal and postnatal care. For example, the behaviours of medical staff were considered to influence women's attendance:

The behaviour of doctors also matters. When we refer the patients to the hospital, the gynecologist's behaviour discourages the patient from further follow-up. We notice that when females meet a good gynecologist or any other doctor, they feel happy and want to do her checkup again. (FGD2_LHWs & LHV)s)

Elders and wider family members were reported to create delays in health-seeking behaviours in attempts to prevent women from giving birth early or having a cesarean, thereby exacerbating the risks for the mother and infant:

If we want to deliver the baby early, then the family complain about why you are delivering the baby so early. Also, why are you delivering the baby through a C-section? Then the family delay the process and finally come to us in a very serious condition. (FGD7_Gynecologists/Obstetricians)

Not following the guidance

Overall patient compliance with medical advice was perceived to be low. Several participants believed this situation to be fueled by the community's mistrust of clinical care as well as their lack of health literacy. Communities were believed to lack knowledge and understanding about the purpose and value of antenatal check-ups, the etiology and pathology of risk factors for SGA, and preventative care:

The most important is that the patient should know about her risk factors. And she should be aware of what she can do for herself. So first if she knows her risk factors then she will be less prone to such problems. But in our society patients are not aware about her previous problems. If she had hypertension in a previous pregnancy, she is not aware that it can happen this time too. If her previous baby was SGA or IUGR she should know that what steps or planning will be required for the next pregnancy. (FGD7_Gynecologists/Obstetricians)

Overall, only 43.6 % of survey respondents agreed that women in their hospitals received any information or advice regarding the prevention of SGA.

In one of the focus groups, the medical professionals considered women's lack of take-up of medical advice to be fueled by *'untrained midwives'* who could minimize the medical advice provided. Wider community members were also perceived to be responsible for non-adherence by discouraging women from having ultrasounds and not paying attention to diet-related advice such as adequate nutrient intake or taking supplements. Moreover, while birth spacing is a preventative measure for SGA, there were cultural taboos surrounding contraception which meant that women would often not comply:

The people in our community are strictly against contraception [...] After cesarean section we counsel the mother that there should be 2 year gap but within a year they come with another pregnancy with many complications. (FGD4_Gynecologists/Obstetricians)

Some participants highlighted pragmatic difficulties that could discourage women from following best practices, such as family responsibilities or lack of money. Others highlighted behavioural issues whereby while the mothers would initially comply, i.e., in taking supplements, this would wane over time, as well as how the following best practice would be undermined by family members:

The mother-in-law strictly dismisses the ultrasound. They tell the pregnant ladies that don't go for ultrasound otherwise your baby will be born abnormal [...] Mothers-in-law don't allow the pregnant female to take supplements during pregnancy. They tell the mothers that medicine can increase your baby weight and it will be very difficult for you to deliver a high-weight baby. (FGD2_LHWs&LHV)s)

Several participants considered how the support of the *'whole family'* was needed to encourage take-up, particularly as Pakistan is a patriarchal society where women tended to prioritize the needs of others over themselves.

Lack of data and reporting

A recurring issue related to the lack of country-specific data. Participants complained about limited research and a lack of screening and documentation which meant; *'we have no proper statistics regarding the prevalence of SGA'* (FGD6_Gynecologists/Obstetricians). Participants referred to how they could only offer an approximation of SGA cases per month (e.g., between *'3 to 5'* or *'30-35'*) due to having *'no idea about exact numbers'* (FGD5_Neonatologists). Similar complaints were also made about a lack of data on the outcomes of babies born SGA:

At the periphery or district level, we have no idea about neonatal death rate, causes and implications. Even pediatricians have no

record of weak babies and their outcomes. (FGD4_Gynecologists/Obstetricians)

Complaints were made about the lack of SGA reporting, despite various other pregnancy-related issues being well-documented:

They used to have registers now I think they have computerized them, so they have statistical records of all the diseases like pregnancy-induced hypertension, diabetic mothers and their fetuses just as cardiac diseases as well as patients coming with some other types of diseases; they have the statistical records with them. They have statistics for diseases like placental abruption, and placenta previa, they have records for like everything. However, they do not have any statistical record for SGA and that is because there is no awareness as they have never thought of it as a problem. (FGD7_Gynecologists/Obstetricians)

Overall, the paucity of information meant it was impossible to plan to attempt correct outcomes for future SGA infants:

How we can control this and what will be the outcome of those SGA infants in future? How can we correct these changes e.g., it is known that these infants are prone to having metabolic disorders, diabetes mellitus, and cardiovascular diseases in future [...] and no such data is available. (FGD4_Gynecologists/Obstetricians)

Another area of concern was how a lack of research meant that there were no standards to benchmark SGA infants in Pakistan. As the threshold of being '*below 10 % percentile*' was based on Western populations whose infants' weights '*are twice ours*', this increased the potential for SGA being misdiagnosed:

We don't have a customized growth chart based on the heights and weights of the Pakistani population. If we want to follow, we will follow the foreign charts. Western people are tall. Their BMI and physique are also different from our population. So, we have no charts. (FGD7_Gynecologists/Obstetricians)

Participants referred to how these significant gaps called for robust research on SGA in Pakistan which could help to elicit the level of need and fuel the impetus for appropriate context-related policies and guidelines:

If the data regarding SGA is recorded and analysed properly then it may be alarming for the hospital, and they will definitely make policies for preventing and managing SGA births. (FGD6_Gynecologists/Obstetricians)

Discussion

In this paper, we present data collected via survey and qualitative methods to explore the use of policies, knowledge, and practices relating to the identification and management of small for gestational age infants (SGA) in Pakistan. Overall, the findings highlight a general lack of awareness of policies to screen, prevent and treat SGA, coupled with complaints about a scarcity of local guidelines leading to disparities in diagnosis and care management. Most survey respondents had not received any training on how to care for SGA: a lack of knowledge was recognised as an issue for all professionals, particularly community staff who acted as primary caregivers for most women in Pakistan. A paucity of care for SGA was associated with a lack of time, staffing, specialism, equipment, and finances. Women were also reported to not access specialist care or adhere to medical advice due to a lack of understanding, distance from healthcare facilities (and associations with poverty) and the influence of sociocultural norms and beliefs. As identified in the work by Sarah Bennett et al.,¹³ 'multisectoral action for health is key to achieve the Sustainable Development Goals (SDGs)' – the two relevant SDGs in an SGA context relating to 'good health and well-being' and 'reduced inequalities'.¹⁴ Overall, the issues reported

highlight the need for systems-level thinking with a multifaceted approach to tackle these individual, community, cultural, professional, and organisational challenges.¹⁵

From an individual and community perspective, women, husbands, family members and community elders need education on the importance of attending regular antenatal check-ups, and how to recognize the signs and complications of SGA for early identification and treatment. However, these factors need to be considered in terms of geographical, financial and cultural barriers to women's access to healthcare in LMICs.¹⁶ The importance of physical-patient communication on health outcomes is emphasised in the wider literature,¹⁷ but poverty, rurality, and conflicting advice can create insurmountable challenges. Furthermore, while women in these settings receive care from community health workers, their lack of education and knowledge to address SGA-related risk factors compounds the challenges these families face. Participants in our study stressed the need for education for all professionals, particularly those in the community. A recent literature review found that education, monitoring during pregnancy, and implementing preventive strategies are as important as biological determinants in risk reduction of SGA births.¹⁸ Training is needed to promote the prevention of SGA, such as through providing affordable solutions to help prevent malnutrition deficiencies¹⁹ and framing advice based on cultural needs so it is acceptable and more likely to be adopted.²⁰

Participatory action research projects to co-produce education materials with families, community elders and community staff would help ensure that the information is feasible and acceptable. Clinical training for community health professionals is essential to identify high-risk women and could involve skill development such as through undertaking ultrasounds and checking the fundal height, before referrals for hospital-based care. However, access to specialist support for women in resource-poor areas also requires financial risk protection schemes that enable women to access essential healthcare without undue financial hardship.²¹

Specialist training is also required for those based in hospital settings to help optimize screening, management and treatment of SGA, and this work needs to be supported by culturally sensitive guidelines.²² In this study, participants noted that the available guidelines were based on high-income populations. Guidelines, together with clinical judgment, are the hallmark of evidence-based practice.²³ Thus, guidelines must offer criteria to diagnose and treat in line with population parameters. While a few participants indicated that there were 'some' local guidelines in operation, there were broader complaints of a lack of research, such as epidemiological studies, in Pakistan. High-quality research as well as rigorous routine data monitoring systems are needed to map the incidence, etiology, and outcomes of SGA babies in Pakistan. This would help to identify the level of need, to understand the causes of SGA, and to inform population-based growth charts for diagnostic purposes. The evidence could also be used as leverage for additional hospital-based specialism and resources needed to care for these high-risk families, as well as to lobby for government-level support such as through financial aid to support dietary and preventive activities.

As a final reflection, and with all areas of healthcare practice, and particularly for those with complex needs, such as SGA, multidisciplinary working is crucial.²⁴ Poor interprofessional collaboration can negatively affect service delivery, patient care and outcomes.²⁵ Multidisciplinary practices for the care and treatment of SGA should include hospital and community healthcare staff such as gynecologists, radiologists, nutritionists, neonatologists, pediatricians, and counsellors to ensure that the women's (and infant's) holistic care needs are met. This could mirror the 'grand rounds' – a formal meeting where clinical cases of more than one patient are discussed²⁶ – with video conferencing utilised to connect those working in the community as needed. The grand rounds could also serve, as currently applied within healthcare, as an important educational and learning tool, as well as serving as an effective strategy for initiating change in patient care.²⁷

Strengths and limitations

The strength of this study is that it is, to the best of our knowledge, the first to explore the policies and practices associated with SGA in Pakistan and from a multi-stakeholder perspective. Data captured by survey and qualitative methods enabled us to gather a broad understanding of how services operate, and rich insights into barriers and challenges faced in this locale. Overall, we were able to capture insights from over 150 participants, and individuals were able to participate in their language (for the FGDs/interviews) to maximize recruitment. Two researchers from the UK and one from Pakistan led the data analysis, with all decisions agreed upon across the team thereby increasing credibility and confirmability of the findings. The limitations are that we did not collect the names of the hospitals where individuals work, so it was difficult to assess how representative the survey results were of practices across the five included regions of Pakistan. Furthermore, while the number of healthcare staff was sizeable for a qualitative study, this was not the case for mothers. We did not collect socio-demographic information from all the study participants, which limits the transferability of the findings. Whilst we know that rurality and poverty are key challenges in accessing healthcare, we do not know whether we were able to gather insights from women with these backgrounds. Future research that explores women's and health care professionals' experiences of caring for SGA babies should cover a broader range of demographic criteria, to enable a more in depth analysis in the context of participants' varied socioeconomic status and education level.

Conclusions

Our findings highlight a general lack of awareness of policies and training in relation to health care professionals' care of SGA babies and this was compounded by a lack of time, staffing, specialism, equipment, and finances in the clinical setting. Women were also reported to not access specialist care or adhere to medical advice due to a lack of understanding, distance from healthcare facilities, and the influence of sociocultural norms and beliefs. Overall, the issues reported highlight the need for systems-level thinking with a multifaceted approach to tackle these individual, community, cultural, professional, and organisational challenges. Future intervention studies may include implementation of country-specific policies, training for healthcare professionals and awareness raising amongst women and community members. It is important to ensure that such interventions are co-designed with the community to ensure that the cultural and societal factors influencing healthcare-seeking behaviours, including the influence of family, community, and socioeconomic status, are recognised and integrated into the design of the intervention.

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CRediT authorship contribution statement

Victoria Hall Moran: Conceptualization, Formal analysis, Funding acquisition, Methodology, Project administration, Writing – original draft, Writing – review & editing. **Gillian Thomson:** Formal analysis, Writing – original draft, Writing – review & editing. **Sadia Fatima:** Conceptualization, Data curation, Investigation, Methodology, Project administration, Supervision, Writing – review & editing, Writing – original draft. **Hamid Habib:** Data curation, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. **Usman Mahboob:** Data curation, Formal analysis, Writing – original draft, Writing – review & editing. **Rubina Nazli:** Data curation, Supervision, Writing – original draft, Writing – review & editing.

Declaration of Competing Interest

I declare that I participated in the design, execution, and analysis of the paper by Hall Moran and colleagues entitled Health professionals and women's knowledge and experiences of caring for small gestational age (SGA) infants in Pakistan, that I have seen and approved the final version and that it has neither been published nor submitted elsewhere. I also declare that I have no conflict of interest, other than any noted in the covering letter to the editor.

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