**ORIGINAL ARTICLE**

# Assessment of Timely Diagnosis and Practices in Pediatric Rheumatology: A Survey of Current Trends and Challenges in Pakistan

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## ABSTRACT

**Objective:** Pediatric rheumatic illnesses comprise a spectrum of inflammatory disorders. Pediatric rheumatology (PR) is still deemed a puzzling field of pediatric healthcare, particularly among underdeveloped regions. This study aimed to address key aspects of pediatric rheumatology care in Pakistan including evaluation of challenges in diagnosis, and identifying the referral systems.

**Study Design:** Cross sectional survey

**Place and Duration of Study:** It was online survey, from October 2024 to December 2024.

**Material and Methods:** This cross-sectional study used an online survey and convenience sampling to recruit 213 pediatricians and healthcare professionals in Pakistan. A structured questionnaire assessed PR diagnosis, referral patterns, and barriers. Participants received the survey link via social media and email, with data analyzed using SPSS version 26, employing descriptive statistics and chi-square tests.

**Results:** Most respondents (68.5%) encountered pediatric rheumatology cases occasionally, and 85.4% collaborated with specialists, though only 5.6% were very familiar with management guidelines. Referral practices were largely driven by challenges, with 56.8% referring when stuck during management and 37.1% referring before treatment. Key barriers to prompt diagnosis included inadequate training (70.4%), low public awareness (61.0%), and shortage of specialized rheumatologists (58.2%). No significant association between familiarity with current guidelines for the management of pediatric rheumatological disorders and educational back ground was found ($r$=0.328).

**Conclusion:** The findings highlight critical barriers to prompt diagnosis of pediatric rheumatological conditions, including limited availability of multidisciplinary teams, a shortage of specialized pediatric rheumatologists, low public awareness of pediatric rheumatic diseases, insufficient awareness among healthcare providers, and inadequate training for pediatricians.

**Key Words:** *Barriers, Challenges, Diagnosis, Pediatric Rheumatology, Practices, Pakistan*

## INTRODUCTION

Pediatric rheumatic illnesses comprise a spectrum of inflammatory disorders including juvenile idiopathic arthritis (JIA). These ailments persist as

the leading cause of acquired disability in children;[1] risk factors for worse prognosis include delays in diagnosis, limited access to suitable treatments, insufficient specialist services, absence of pertinent guidelines being accessible, and child residing in regions with poorer socioeconomic conditions.[2] Childhood-onset rheumatic diseases are among the chronic conditions associated with a significant risk of mortality and long-term disability if not promptly identified and adequately managed. These conditions impact an estimated 300,000 children in the United States.[3]

In low- and middle-income countries, accurately assessing the prevalence of pediatric rheumatic diseases is often challenging.[4] This difficulty is largely attributed to limited awareness among healthcare providers regarding rheumatic conditions in children, insufficient access to pediatric rheumatology services, and a greater focus on addressing communicable diseases rather than non-communicable rheumatic disorders.[5] Additionally, the overlapping presentation of musculoskeletal (MSK) symptoms key indicators of rheumatic diseases with other systemic conditions such as metabolic, endocrine, neoplastic, and infectious disorders further complicates timely diagnosis.[6]

There are significant workforce issues worldwide. There are still restricted options for pediatric rheumatologists in Southeast Asia,[7] hence many children with rheumatic ailments are managed primarily by adult rheumatologists and general pediatricians.[8] Pediatric rheumatology is still deemed a puzzling field of pediatric healthcare, particularly among underdeveloped regions. Long-term complications typically result from delayed diagnosis, referral, and treatment of rheumatic conditions.[9] Notably, in Asia, there is one pediatric rheumatologist for every 26 million children; this disparity markedly contrasts with the standards for Europe and North America, with one pediatric rheumatologist per 0.42 and 0.25 million children correspondingly.[10]

Currently, various care guidelines and treatment protocols for children with rheumatic diseases have been developed by international pediatric rheumatology organizations, primarily comprising experts from high-resource and affluent countries (HRIC).[11] However, these recommendations often fail to align with the realities of clinical practice in moderately resourced countries (MRIC) and low-resource income countries (LRIC), where healthcare systems face significant constraints and competing priorities in service delivery.

This study aimed to address key aspects of pediatric rheumatology care in Pakistan through a multi-dimensional framework. It emphasized diagnostic practices, including evaluation of challenges in diagnosis, and identifying the referral systems. Additionally, the research investigated the training needs of general pediatricians to enhance their competence in managing these conditions.

## MATERIAL AND METHODS

After the approval, as per IRB no: 2024/09/R-43, this study was conducted as a cross-sectional analysis using an online survey and a convenience sampling method to recruit pediatricians and healthcare professionals involved in pediatric care in Pakistan. Data were collected through a structured questionnaire regarding pediatric rheumatology (PR) diagnosis and referral patterns and practices.

The survey was disseminated to healthcare providers, including doctors, who were either directly, involved in PR clinical care or part of general pediatric networks likely to encounter children with rheumatic diseases. Participants received the survey link via professional social media platforms (e.g., WhatsApp™) or email and were encouraged to share the link with colleagues. Anonymity and confidentiality were maintained throughout the data collection process.

The survey included questions about participants' educational background, referral policy, encounter of pediatric rheumatology patients, and the proportion of their practice dedicated to PR patients. It also sought insights into barriers contributing to delays in the diagnosis of pediatric rheumatic conditions, specifically focusing on factors affecting the timeliness of referrals, specialist access, and clinical evaluation. Open-ended questions allowed respondents to provide free-text comments for a more comprehensive understanding of these issues. Data was analyzed using SPSS version 26. Descriptive Statistics

were utilized to present the data. Chi square test was applied to analyze the difference between familiarity with current guidelines on management of pediatric rheumatology conditions and educational background.

## RESULTS

A total of 213 participants were included in the study. Among them, 19.7% were male (n=42), and 80.2% were female (n=171). Participants' educational backgrounds varied widely, with the majority holding FCPS qualifications (68.5%, n=146). Other notable qualifications included MBBS/general practitioners (9.85%, n=21), MCPS (7.04%, n=15), and DCH (0.42%, n=9). The remaining participants held a range of less common qualifications, including MD Pediatrics (n=11), MRCP (2.34%, n=5), and various other specialized training certifications, each representing 0.5% of the total sample.

**TABLE 1: Descriptive statistics of participants**

| | | Frequency | Percentage |
|---|---|---|---|
| Gender | Male | 42 | 19.7 |
| | Female | 171 | 80.2 |
| Educational background | FCPS Pediatricians | 146 | 68.5 |
| | FCPS Trainee | 6 | 2.81 |
| | MBBS/GP | 21 | 9.85 |
| | DCH | 9 | 0.42 |
| | MCPS | 15 | 7.04 |
| | MRCP | 5 | 2.34 |
| | MD | 11 | 5.16 |
| | Total | 213 | 100.0 |

The table 2 presented the responses to three questions regarding the management of pediatric rheumatological conditions. When asked how frequently they encountered pediatric patients with rheumatological conditions in their practice, 16.0% (34 respondents) reported encountering them frequently, 68.5% (146 respondents) occasionally, and 15.5% (33 respondents) rarely. Regarding collaboration with rheumatology specialists or other healthcare professionals, 85.4% (182 respondents) indicated that they collaborated, while 14.6% (31 respondents) did not. Lastly, when asked about their familiarity with current guidelines for managing pediatric rheumatological disorders in Pakistan, 15.5% (33 respondents) stated they were not familiar at all, 78.9% (168 respondents) were somewhat familiar, and 5.6% (12 respondents) were very familiar.

**TABLE 2: Descriptive statistics of diagnosis Practices**

| Variables | | Frequency | Percentage |
|---|---|---|---|
| How frequently do you encounter pediatric patients with rheumatological conditions in your practice? | Frequently | 34 | 16.0 |
| | Occasionally | 146 | 68.5 |
| | Rarely | 33 | 15.5 |
| Do you collaborate with rheumatology specialists or other healthcare professionals when managing pediatric rheumatology cases? | No | 31 | 14.6 |
| | Yes | 182 | 85.4 |
| How familiar are you with current guidelines for the management of pediatric rheumatological disorders in Pakistan? | Not at all | 33 | 15.5 |
| | Somewhat | 168 | 78.9 |
| | Very | 12 | 5.6 |
| **Total** | | 213 | 100.0 |

Table 3 reported the responses to a question regarding the conditions under which healthcare professionals refer pediatric rheumatology cases. The majority of respondents, 56.8% (121 respondents), indicated they refer cases "when they feel as if they are stuck." A significant proportion, 37.1% (79 respondents), reported referring patients before treatment. Several other responses, each representing 0.5% (1 respondent), include referral after making their own plan to reinforce the diagnosis, after suspicion, when eye treatment is started, before the use of oral medication, depending on the stage of presentation and case scenario, further investigation and the attendant's wish, when the patient is not responding to medicine, or when not treating rheumatological disorders. Other less common scenarios for referral included not having lab facilities available, referring to confirm the diagnosis, when the patient outgrows to adult age, or when complaints persist after multiple visits.

**TABLE 3: Descriptive statistics of referral policy**

| | Frequency | Percentage |
|---|---|---|
| After making my own plan to reinforce the diagnosis and to check if anything is missing, then put on treatment and refer to rheumatology for further management and follow up | 1 | 0.5 |
| After suspicion | 1 | 0.5 |
| As soon as I start eye treatment and before use of oral med | 1 | 0.5 |
| Before treatment | 79 | 37.1 |
| Depends upon the stage of presentation....and the case scenario. | 1 | 0.5 |
| Further investigation and attendant's wish | 1 | 0.5 |
| Not responding to medicine | 1 | 0.5 |
| Not treating rheumatological disorders | 1 | 0.5 |
| Referral after basic relevant investigations | 1 | 0.5 |
| To confirm the Diagnosis | 1 | 0.5 |
| We referred for further discussion or if patient outgrow to adult age | 1 | 0.5 |
| When pts complain still exists even after 2 or more visits. | 1 | 0.5 |
| When we can't manage | 1 | 0.5 |
| When we dont have lab facilities available | 1 | 0.5 |
| When you feel as if you are stuck | 121 | 56.8 |
| Total | 213 | 100.0 |

Table 4 showed barriers to prompt diagnosis of pediatric rheumatic diseases as reported by healthcare professionals. The most significant barrier identified was inadequate training on pediatric rheumatic diseases for pediatricians, with 70.4% (150 respondents) indicating this as an issue. Other notable barriers included a shortage of specialized pediatric rheumatologists, reported by 58.2% (124 respondents), and low public awareness of pediatric rheumatic diseases, cited by 61.0% (130 respondents). Additionally, 53.9% (115 respondents) pointed to insufficient awareness of pediatric rheumatic diseases among healthcare providers, and 47.9% (102 respondents) mentioned the limited availability of multidisciplinary pediatric rheumatology teams.

**TABLE 4: Perceived main barriers and challenges of pediatric rheumatology timely diagnosis**

| Barrier to prompt diagnosis of pediatric rheumatic diseases | Frequency | Percentage |
|---|---|---|
| Limited availability of multidisciplinary pediatric rheumatology teams | 102 | 47.9 |
| Shortage of specialized pediatric rheumatologists | 124 | 58.2 |
| Low public awareness of pediatric rheumatic diseases | 130 | 61.0 |
| Insufficient awareness of pediatric rheumatic diseases among health providers | 115 | 53.9 |
| Inadequate training on pediatric rheumatic diseases for pediatricians | 150 | 70.4 |
| Total | 213 | 100.0 |

Table 5 presented the familiarity of healthcare professionals with the current guidelines for the management of pediatric rheumatological disorders in Pakistan, categorized by their educational background. Of the 213 respondents, 39 (18.3%) reported they were not familiar at all with the guidelines, 156 (73.2%) were somewhat familiar, and 18 (8.4%) were very familiar. Among those with an FCPS qualification, the majority (115 respondents, 79.3%) were somewhat familiar with the guidelines, while 19 were not familiar at all, and 12 were very familiar. In the MBBS/GP group, 14 respondents were somewhat familiar, and 7 were not familiar, with no respondents being very familiar. Other qualifications, such as MD, MCPS, and MRCP, showed varying levels of familiarity, but no respondents in these categories were very familiar with the guidelines. The statistical analysis, including Pearson Chi-Square (43.418) and Likelihood Ratio (33.518), revealed no significant association between educational background and familiarity with the guidelines ($p > 0.05$). However, 88.9% of the cells in the analysis had expected counts of less than 5, which could influence the interpretation of these results.

**TABLE 5: Chi square test analyzing difference between familiarity with current guidelines and educational background**

| | | How familiar are you with current guidelines for the management of pediatric rheumatological disorders in Pakistan? | | | Total |
|---|---|---|---|---|---|
| | | Not at all | Somewhat | Very | |
| Educational Background | FCPS | 19 | 115 | 12 | 146 |
| | FCPS Trainee | 2 | 3 | 1 | 6 |
| | MBBS/GP | 7 | 14 | 0 | 21 |
| | DCH | 2 | 6 | 1 | 9 |
| | MD | 3 | 7 | 1 | 11 |
| | MCPS | 5 | 8 | 2 | 15 |
| | MRCP | 1 | 3 | 1 | 5 |
| **Total** | | **39** | **156** | **18** | **213** |

| | Value | df | Asymptotic Significance (2-sided) |
|---|---|---|---|
| Pearson Chi-Square | 43.418[a] | 40 | 0.328 |
| Likelihood Ratio | 33.518 | 40 | 0.756 |
| N of Valid Cases | 213 | | |

a. 56 cells (88.9%) have expected count less than 5. The minimum expected count is .06.

## DISCUSSION

This study represents the first comprehensive survey targeting timely diagnosis practices, barriers, and challenges in pediatric rheumatology (PR) in Pakistan. It is also the inaugural study describing PR clinical care and training across Asian regions. The findings highlight multiple critical challenges within the field and emphasize the need for urgent attention to address these gaps. Our results demonstrated a significant paucity of trained pediatric rheumatologists and specialist multidisciplinary teams (MDTs), which were identified as the primary barriers to improving PR clinical care in Pakistan. The lack of these essential resources limits the ability to deliver comprehensive care for children with rheumatic diseases. Pediatric rheumatologists play a vital role not only in direct patient care but also in education and training leadership, advocacy, policy development, and research.[12] These activities are crucial for capacity building and improving clinical outcomes in pediatric rheumatology.

Globally, previous studies, predominantly from high-resource income countries (HRICs) and middle-resource income countries (MRICs), have highlighted the scarcity of pediatric rheumatologists.[13] This shortage is most acute in low-resource income countries (LRICs) and regions like Africa and Asia unfortunately, home to some of the most populous countries and the largest burden of children affected by rheumatic diseases.[14] The findings from this study align with those observations and underscore the dire need for interventions tailored to resource-limited settings like Pakistan.

The establishment of more PR training programs is critical. Encouraging and supporting pediatricians to specialize in PR remains a significant challenge due to competing healthcare priorities and the overall shortage of pediatricians in LRIC and MRIC regions.[15] In Pakistan, where healthcare resources are already stretched thin, it is imperative to prioritize the development of training pathways and provide incentives for pediatricians to pursue further specialization in PR.[16] Collaborative efforts between government bodies, academic institutions, and international organizations could play a pivotal role in this regard.

Increasing awareness and knowledge about PR among general pediatricians, orthopedic surgeons, adult rheumatologists, nurses, and allied health professionals (AHPs) is equally essential. These healthcare professionals are often the first point of contact for children with potential rheumatic diseases and must be equipped with the knowledge and skills to make

accurate diagnoses, provide initial care, and refer to specialists where available.[17] Targeted education and training programs tailored to the clinical context of Pakistan could address this gap effectively.

In addition to improving healthcare professional training, raising awareness among the general population is crucial to encourage early healthcare-seeking behavior. Delays in presentation often exacerbate disease progression, leading to poorer outcomes.[18] Public awareness campaigns, such as those conducted on World Young Rheumatic Disease (WORD) Day, could help disseminate information about PR and its symptoms, thereby promoting earlier diagnosis and intervention.[19] It is worth noting that PR training is currently being developed in some South-East Asian countries, including Singapore, Malaysia, the Philippines, and Thailand.[20] Pakistan can benefit from learning from these countries' experiences while tailoring solutions to its unique challenges. Collaborative regional efforts may further strengthen PR care and training across Asia.

Identical difficulties have been reported on a global scale. With only one pediatric rheumatologist per about 26 million children, a 2019 survey conducted throughout Southeast Asia and the Asia-Pacific region revealed a severe shortage of these specialists, in sharp contrast to the 0.25–0.42 per million average in Europe and North America.[10] Clinical capacity was directly hampered by the lack of multidisciplinary teams and the lack of specialized assistance. According to a study of pediatricians at Sheikh Khalifa Medical City in the United Arab Emirates, the majority of them had insufficient confidence in their ability to diagnose or treat rheumatic disorders, and 87% had less than a year of expertise in pediatric rheumatology. According to that survey, 92.6% of participants supported the creation of formal training programs.[21]

Diagnosis delays seem to be universal and have major repercussions. Referral times in the UAE are obviously prolonged by the inexperience of the providers. According to Israeli studies, it takes an average of 56 days from the onset of symptoms to the diagnosis of juvenile idiopathic arthritis; several doctor visits usually occur before the right referral is made, particularly if specialists are not consulted right away.[22] Only four pediatric rheumatology facilities are established nationwide in Singapore, and public and clinician knowledge is still low, which discourages referrals and creates diagnostic bottlenecks.[23]

In conclusion, this study highlights significant barriers to improving pediatric rheumatology care in Pakistan, including a shortage of trained specialists and MDTs, inadequate training, and limited public awareness. Addressing these challenges requires a multi-faceted approach involving capacity building, education, advocacy, and public health campaigns. By prioritizing pediatric rheumatology in national healthcare policies and fostering international collaboration, Pakistan can pave the way for better outcomes for children suffering from rheumatic diseases.

**Limitations:** This study has certain limitations that should be recognized. Primarily, there may be selection bias due to restricted number and geographic distribution of pediatric rheumatologists in Pakistan, which may not represent the broader population of healthcare providers. Additionally, the usage of surveys as primary data collection method might not capture the depth and complexity of the challenges faced in pediatric rheumatology. Conducting interview-based surveys or qualitative studies could provide more in-depth insights into the barriers and potential solutions.[19] Lastly, the findings are specific to Pakistan and may not be entirely generalizable to other countries in the South-East Asia or Asia-Pacific regions, although similar challenges are likely to exist in resource-limited settings.[20]

## CONCLUSION

This study assessed current trends and challenges in timely diagnosis practices for pediatric rheumatology in Pakistan. The findings highlight critical barriers, including limited availability of multidisciplinary teams, a shortage of specialized pediatric rheumatologists, low public awareness of pediatric rheumatic diseases, insufficient awareness among healthcare providers, and inadequate training for pediatricians. Addressing these issues through targeted capacity building, improved training programs, and public awareness initiatives is essential to enhance the timely diagnosis and

management of pediatric rheumatic diseases in Pakistan.

**Conflict of interest:** None

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