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Are people getting quality thalassemia care in twin cities of Pakistan? A comparison with international standards

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Statement of Problem: Prognosis of beta thalassemia patients is quite poor in Pakistan. Patients survive to only 25 years on average in the country as compared to developed world where survival has reached beyond 50 years. Better quality care is a known predictor of better survival and reduced transmission of thalassemia. This study was conducted to determine if thalassemia patients were getting quality care in Rawalpindi and Islamabad, Pakistan as per international standards.

Methods: A cross sectional study was conducted on 302 thalassemia patients from May to August, 2016 in five healthcare facilities catering the needs of thalassemia patients in Rawalpindi and Islamabad. Technique of probability proportional to size was used to calculate participants per facility. Interview based structured questionnaire was developed using standards of thalassemia care.

Results: Results showed that almost half of the thalassemia patients (47.4%) were getting either poor or very poor quality of care. On average patients were getting only half of the possible quality services (56.7%). The most deficient quality areas were thalassemia screening and counseling services and management of complications. Better quality of care was likely to be received by those who are educated, visiting private facilities and those who are visiting facilities in Islamabad.

Conclusion: The quality of care provided to thalassemia patients was well below the international standards for the care of thalassemia. There is a need to take urgent action to improve quality of care in the country.

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