EXPLORING THE UTILITY OF TELEMEDICINE FOR PEDIATRIC NEPHROLOGY AT AIIMS JODHPUR: A STUDY OF PATIENT OUTCOMES, SATISFACTION, AND COMPLIANCE



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DECLARATION BY THE CANDIDATE

I hereby declare that the thesis titled "Exploring the utility of telemedicine for Pediatric Nephrology at AIIMS Jodhpur: A study of patient outcomes, satisfaction, and compliance" embodies the original work carried by the undersigned in All India Institute of Medical Sciences Jodhpur, (Rajasthan)

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CERTIFICATE

This is to certify that the thesis titled "Exploring the utility of telemedicine for Pediatric Nephrology at AIIMS Jodhpur: A study of patient outcomes, satisfaction, and compliance" is the bonafide work of Dr. Vishnu Dev P. M Post Graduate student in the Department of Pediatrics, All India Institute of Medical Sciences, Jodhpur under our guidance and supervision.

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ALL INDIA INSTITUTE OF MEDICAL SCIENCES, JODHPUR

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ABBREVIATIONS

S. No.	Short Form	Full Form		
1	WHO	World Health Organization		
2	AIIMS	All India Institute of Medical Sciences		
3	OPD	Out Patient Department		
4	HIS	Hospital Information System		
5	RCT	Randomized Controlled Trial		
6	ESRD	End-stage renal Disease		
7	TUQ	Telemedicine Usability Questionnaire		
8	CKD	Chronic Kidney Disease		
9	CAKUT	Congenital anomaly of Kidney and Urinary tract		
10	RTA	Renal Tubular Acidosis		
11	SSNS	Steroid Sensitive Nephrotic Syndrome		
12	SDNS	Steroid Dependent Nephrotic Syndrome		
13	SRNS	Steroid Resistant Nephrotic Syndrome		
14	SLE	Systemic Lupus Erythematosus		
15	UTI	Urinary tract Infection		
16	INR	Indian Rupee		
17	KFT	Kidney function test.		

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INTRODUCTION

WHO defines telemedicine as 'The delivery of healthcare services where distance is a critical factor, by all healthcare professionals using information and communications technologies for the exchange of valid information for the diagnosis, treatment, and prevention of disease and injuries, research and evaluation, and the continuing education of healthcare workers, to advance the health of individuals and communities [1].

Modern telemedicine originated in 1905. The first clinical application of telemedicine was the long-distance transfer of electrocardiograms. Then radio consultations were used for patients aboard ships and on remote islands from medical centres. The first Organized telemedicine program started in the United States in the late 1950s [2].

Since then, telemedicine has evolved. The advancement in wireless broadband technology, cell phone, and the Internet has helped telemedicine. Regardless of their educational status, people started learning to use these, which have become part of daily life [3].

With a population of more than 120 crores, India is the second most populous nation in the world. There are fewer doctors available to serve this group. This deficit makes it difficult to distribute healthcare services adequately and equally. By exchanging accurate information for the diagnosis, treatment, and prevention of disease and injuries, as well as for research and evaluation and the ongoing education of healthcare professionals, telemedicine is a crucial tool that can address this disparity and enhance the delivery of healthcare services [3].

The Telemedicine system comprises an interface between hardware, software, and a communication channel to connect two places geographically and enable information exchange and teleconsultancy between two sites [4]. The various benefits of Telemedicine are mentioned in table 1.

Table 1 :Benefits of Telemedicine[4]

- Easy access to remote areas
- Using telemedicine in peripheral health setups can significantly reduce the time and costs of patient transportation.
- Monitoring home care and ambulatory monitoring
- Improves communications between health providers separated by distance
- Critical care monitoring where it is not possible to transfer the patient
- Continuing medical education and clinical research
- A tool for public awareness
- A tool for disaster management
- Second opinion and complex interpretations
- The most extraordinary scope for telemedicine technology is that it can bring closer significant expertise.
- Telementored procedures-surgery using hand robots
- Disease surveillance and program tracking
- It offers a chance for healthcare delivery to be standardized and equitable across regions, continents, and inside particular nations.

Follow-up of Renal diseases usually needs detailed history and lab workup. An electronic setup may be adequate for nephrological evaluation, albeit it cannot replace a thorough examination. Telemedicine appears appropriate for patients undergoing local evaluation or routine follow-up in the hospital OPD. To ensure safe and prompt solutions to patients' problems, it should strive to deliver efficient services. To assess patient satisfaction, there should also be a feedback mechanism in place [5].

There is also a need to assess the clinical outcomes after teleconsultations. It is crucial to determine if these consultations failed to assess the patient's clinical condition and ensure accurate medical advice to the patients. Some studies concluded telemedicine was effective in rheumatology, Diabetic, and hypertensive patients [6]. Patients with

Renal disease, who require specialist care, and live far away from their nephrologist had less access to therapy, lower clinic visit compliance rates, and more significant risks of mortality and hospitalization compared to those who are close to their nephrologist [7].

Satisfaction is an accepted indicator of the performance of a healthcare service. It reflects patients' values and expectations regarding various aspects of health service. The patients are satisfied when there is a match between the expected and received care [8]. Thus the level of satisfaction is heavily influenced by the patient's actual experiences.

Patient satisfaction influences the quality of care provided regarding his Complaints. Satisfaction surveys provide information about the patient's concerns and areas where a specific service must be improved to improve outcomes. Also, by understanding the patient's concerns, we can clear some misconceptions about the patient, which may have led to poor satisfaction.

Higher patient satisfaction leads to benefits for the health industry in several ways.

Patient loyalty is a result of patient satisfaction. Satisfied patients are more likely to continue the medical care services, have a better relationship with the provider, and have better treatment adherence. Satisfied patients will cooperate better with the treating doctor and is better at disclosing relevant information.

Increased patient retention according to the Technical Assistant Research Programs (TARPs), if we successfully serve one client, the word spreads to four more. If we lose one customer, we lose ten, even more, if the issue is severe. Therefore, to maintain parity, we must please three additional patients for everyone we irritate.

Price conflicts are less likely to affect them. There is enough data to support the claim that companies with high customer loyalty can demand a higher price without suffering a loss in revenue or market share. A survey done in Voluntary Hospitals of America found that over 70% of people would pay more to consult a good doctor. That organizations with high customer loyalty can command.

Consistent profitability - In the USA, it is estimated that losing a patient due to dissatisfaction can cost a clinic over \$200,000 in lost revenue throughout its existence.

Higher productivity is a result of higher workforce morale and lower staff turnover.

Lower risk of malpractice claims: Patient satisfaction scores and medical malpractice claims are inversely correlated.

Accreditation issues - It is now widely acknowledged that the focus of all accreditation organizations, including the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), the National Accreditation Board for Hospitals (NABH), and the International Organization for Standardization (ISO), focuses service quality.

Greater personal and professional satisfaction - we are undoubtedly happier when our care results in improvements for our patients [9].

Compliance or adherence, as it relates to health care, is the extent to which a person's behaviour coincides with medical or health advice [10]. Medication compliance is critical for all aspects of pediatrics, specifically in successful treatment, disease prevention, and health promotion. Increasing the efficiency of adherence measures may have a significantly higher impact on population health than any improvement in a particular medical treatment, according to the WHO's 2003 study on drug adherence. Contrarily, nonadherence causes subpar clinical results, a rise in morbidity and mortality rates, and unnecessary medical costs. Adherence can be measured in a variety of ways. In many situations, objective measurements, such as dose counts, pharmacy records, electronic monitoring of medication administration (such as the Medication Event Monitoring System, MEMS), and drug concentrations, appear to be the most accurate indicators of a patient's medication-taking behaviour. Patient interviews, physician or family reports, self-report adherence scores, and patient interviews are all examples of subjective measures of adherence. These measures might pinpoint the precise causes of a patient's nonadherence. Subjective measurements are less expensive and more easily used[11]. In telemedicine, if the technologies are available, it is straightforward for the patient to get an expert opinion as it avoids travel and decreases tithe consumption of the patient to get an expert opinion. These factors are generally assumed to improve compliance but have not been studied in pediatrics in telehealth encounters for renal diseases.

Compared to in-person appointments, telemedicine has many benefits for patients who live far from the hospital. Reduced costs for patients and their families in terms of travel, lodging, and out-of-pocket expenses [12]. Access to health treatment is frequently hampered by transportation issues, which are worse for underprivileged populations[13]. Also, patients from a long distance need an accommodation to get better healthcare access, which adds to their financial burden. The more the distance or longer the time spent for better healthcare, the more the day of work lost and wages lost.

Telemedicine has been utilized for over three decades in various forms across various countries. However, the system has never been a standard of care and has only gained increasing popularity with the advent of the COVID-19 pandemic. It is a new service, and almost all practitioners use it with only a few guidelines. The provision of this service is a new venture at AIIMS Jodhpur piloted in April 2020 and formally launched in June 2020

This study is to understand the outcome of patients with renal problems seeking telemedicine consultation at the Pediatrics OPD of AIIMS Jodhpur. We also intend to assess their satisfaction with the service and compliance with the treatment advised.

REVIEW OF LITERATURE

Telemedicine is a century-old modality. There are many advances in technology and means to provide services, such that its increasing use has become applicable in recent times. There are studies that found that Telemedicine is an effective alternative to an in-person visit. The modality is useful and effective in managing chronic diseases in remote regions, in situations requiring social distancing (like infectious diseases), and in providing subspecialty care for patients from remote and geographically isolated areas.

Below is a brief review of how telemedicine has found its place in various aspects of medical care; described in table 2.

S.	Author (Year	Study Title	Study	Results/Observations	Limitations	Outcome
No)/Journal [ref]		population			
1	McLean S et al	The impact of	80/	No significant difference between	Studies have not clearly	Need for further long-
	(2013)/	telehealthcare	1782	the outcomes with telehealth	described the level of	term studies to
	PloS one[14]	on the quality	reviews	compared to an in-person visit.	telemedicine	determine whether the
		and safety of			interventions made to	detected benefits are
		care: a			the patient.	time sustained.
		systematic			Many studies were	
		overview			done for short periods.	
2	Lunney M et al	Impact of	After	No differences in laboratory	Most studies reviewed	The study reported the
	(2018)/	Telehealth	screening,	parameters / reduced or similar rates	lacked a detailed	potential benefits of
	American Journal	interventions	10 studies	of hospitalization with telehealth.	description of the	telehealth in ESRD.
	of Kidney	on Processes	were	8 studies evaluated the addition of	delivery of routine care,	
	Diseases.	and Quality of	reviewed 7	telehealth to usual care, in which	which made it difficult	
	[15]	Care for	RCTs, and	there were mixed results.	to identify how	
		Patients with	3 cohorts.		telehealth could be	
		ESRD.	Population		used to improve or	
			ranged		replace other elements	
			from n=11		of ESRD care.	
			to n=135			

Table 2: Studies on patient outcomes and utilisation of telemedicine

S. No	Author (Year)/Journal [ref]	Study Title	Study population	Results/Observations	Limitations	Outcome
3	Tan J et al (2018)/ American Journal of Nephrology [7]	Telenephrology : Providing Healthcare to Remotely Located Patients with Chronic Kidney Disease	n=112 in the telenephrol ogy group. Median age- 68.5yrs (IQR:63 79) n=116 in the urban in person visits Median age 69 years (IQR: 62.5-81)	53.1% of visits to the geographically remote renal clinic were cancelled or were "no-shows." This was reduced to 28% after the addition of telemedicine. With telenephrology, it increased to 71.9% from 61%). The outcome of death, ESRD, or doubling of Cr was similar between both groups (p = 0.96) over 2 years of follow- up.	Retrospective, single- centre nature Small sample size Primarily male, the veteran population limits its generalizability The self-selection bias The demographic and clinical differences observed in a suburban/rural population from Hudson Valley vs an urban population from the Bronx.	While maintaining comparable renal results, remote CKD therapy provided through tele- nephrology promotes renal clinic visit adherence.

S. No	Author (Year)/Journal [ref]	Study Title	Study population	Results/Observations	Limitations	Outcome
4	AlAzab R et al (2016)/ Rural and Remote Health[16]	Telenephrolog y application in rural and remote areas of Jordan: benefits and impact on quality of life	N=64, 16-90 years	For 31.2% of patients, the treatment strategy was modified from that of the referring healthcare provider. Teleclinics benefited them with decreased waiting time and cheaper costs (96.9% and 98.4%, respectively). A high degree of satisfaction was indicated [Score 71.2 to 100 and had a mean of 96.8 (standard deviation: 4.8).] The mean SF8 (quality-of-life questionnaires -short form) (SF- 8)score significantly rose from 33.1 to 45.0 after 2 months of consultations (p=0.019).	Short study period (September 2013- January 2014) Patients were not compared to a group who were not treated by telenephrology	Increase access to healthcare. Assist in making accurate diagnoses and establishing treatment plans Linked to the higher quality of life in Jordan's rural areas.

S. No	Author (Year)/Journal [ref]	Study Title	Study population	Results/Observations	Limitations	Outcome
5	Kaeley N et al(2021)/ Journal of Family Medicine and Primary Care [17]	The current scenario, future possibilities, and applicability of telemedicine in hilly and remote areas in India	Not reported	The information was synthesized on telemedicine across India related to future possibilities of telemedicine, challenges in hilly areas, and national initiatives.	Not reported	Great impact on the rural population, especially in hilly and remote areas of India. Offers cost-effective as well as good quality care.
6	Ma Y et al (2022)/ BMC Medical Informatics and Decision Making[6]	Telemedicine application in patients with chronic disease: a systematic review and meta- analysis	15 articles reviewed	Interventions used: Telemedicine consultation and telemonitoring. Improved self-management in patients with rheumatoid arthritis. The indices of (HbA1c) improved after 12 months of intervention (MD= 0.84; 95% CI= 1.53,0.16) and that systolic blood pressure decreased after 6 months of intervention (MD= 6.71; 95% CI= 11.40,2.02)	No clear mention of intervention done with the help of telemedicine	When telemedicine consultation and telemonitoring methods were utilized, they had a favourable impact on the management of diabetes, hypertension, and rheumatoid arthritis.

Randomized controlled trials are done to compare the benefit of telemedicine in providing supportive care and patient education. Many of the studies show the positive effects of telemedicine. These are a few studies among them, described in table 3.

S. No	Author (Year)/Journal [ref]	Study Title	Study population	Results/Observations	Limitations	Outcome
1	Chow SK et al (2010)/ Journal of advanced nursing[18]	Health-related quality of life in patients undergoing peritoneal dialysis: effects of a nurse-led case management program	n=85 (43 in the study group and 42 controls)/a ge group 23-78 years.	Control group - standard routine care. Study group - comprehensive standardized education before discharge and a 6-week standardized telephonic follow-up by Nurse. Symptoms/problems, effects of kidney disease, sleep, role- physical, pain, emotional well- being, and social function- were significant within the groups Interaction effects were substantial for staff encouragement, patient satisfaction, and sleep- randomized function.	Placebo was not provided to the control group. The Control group should also have followed up with a phone call without discussing the disease-related issues.	Significant improvement inpatient satisfaction and social functioning domain

Table 3: Randomised Control Studies on outcome and utilisation of Telemedicine

S. No	Author (Year)/Journal [ref]	Study Title	Study population	Results/Observations	Limitations	Outcome
2	Li J et al (2014) /Peritoneal Dialysis International [19]	Effects of post- discharge nurse-led telephone supportive care for patients with chronic kidney disease undergoing peritoneal dialysis in China: a randomized controlled trial	n=135 69 in the study group and 66 in the control group and /age group 22-76 years	Control group- routine care, Study group - Nurse -led telephonic follow-up. There were statistically significant effects for symptom/problem, work status, staff encouragement, patient satisfaction, and energy/fatigue in KDQOL-SF and 84-day (12- week) clinic visit rates between the two groups. Significant improvement to the control group for sleep, staff encouragement at 6 weeks and 12 weeks after discharge, pain at 6 weeks, and patient satisfaction at 12 weeks after discharge.	The study was done in 2 local hospitals alone, so can't generalize the findings The outcome was self-reported.	Significant improvement inpatient satisfaction and social functioning domain

S.	Author (Year	Study Title	Study	Results/Observations	Limitations	Outcome
No)/Journal [ref]		population			
3	Jahromi MK et	Effect of	n=60	Study group - standard care.	Small sample size.	The outcome of this
	al (2016)/Global	Nurse-Led	30 in both	Control group- a phone call	No placebo.	experiment is
	Journal of	Telephone	the control	from the nurse at 30 days.	Not mentioned what	anticipated to
	Health	Follow-ups	and study		was communicated	contribute new insights
	Science[20]	(Tele-Nursing)	group	Significant differences were	by phone.	to help hemodialysis
		on Depression,		observed between the two		patients receive
		Anxiety, and		groups in the post-test		excellent follow-up
		Stress in		regarding the dimensions		care to enhance their
		Hemodialysis		scores of the DASS scale.		emotional and physical
		Patients		(Depression anxiety and stress		well-being.
				scale)		

Telemedicine is also being utilized in pediatric patients in different branches. This study is in pediatric patients with renal-related diseases. We have reviewed articles on utilization in pediatric nephrology. There are studies done in pediatric nephrology that showed the benefit and efficacy of telemedicine; described in table 4.

S. No	Author (year)/ journal	Study Title	Study Population	Observations	Limitations	Conclusion
1	Braverman J et al. (2011)/ Journal of telemedicine and telecare [21]	A study of online consultations for pediatric renal patients in Russia	n=70, 1month- 17years	1	Telemedicine service is limited to a single care provider, single language, and basic technology. Overdiagnosis. Not discussed regarding liabilities and cost- effectiveness	Telemedicine could be used in the future; will be more useful for the underserved. Telemedicine is limited by overdiagnosis.

 Table No.4:
 Studies on the utilisation of telemedicine in Pediatric Nephrology

S. No	Author (year)/ journal	Study Title	Study Population	Observations	Limitations	Conclusion
2	Trnka P et al (2015)/ BMC nephrology[12]	A retrospective review of telehealth services for children referred to a pediatric nephrologist	n=168 3 months - 24 years Median of 8 years.	From 2004 – 2013, 318 teleconsults on 168 patients. CAKUT (30 %), nephrotic syndrome (16 %), kidney transplant (12 %), and urinary tract infection (9 %) were the most common diagnoses. Cost savings with telehealth were \$31,837 in 2013 (average saving of \$505 per consultation).	They just mentioned the outcome of a consultation, not the disease Additional costs to the family, such as time off work, parking, fuel, and meals were not included in this study.	Pediatric telenephrology is a practical and cost- effective tool for patient evaluation and follow-up. The advantages include better patient and family access to pediatric nephrology services, educational opportunities for the local medical teams, and significant financial savings for the health system.

S. No	Author (year)/ journal	Study Title	Study Population	Observations	Limitations	Conclusion
3	Mittal A et al (2020)/ Journal of Family Medicine and Primary Care[22]	Telemedicine during COVID-19 crisis in Resource-poor districts near Indo-Pak border of western Rajasthan	n=67	23% (13/57) required urgent consultation (7 relapses, 6 others). 56% (32/57) needed routine appointments of which 33% (11/32) needed modification of their drug doses. Four children (7%) required an in-person visit (for IV medications, biopsy, and management of Complications of Nephrotic syndrome) and were called to the hospital. Only 8/57 (14%) children did not require immediate consultation as they had an in-person visit just before lockdown.	Limited by the study period which was during the lockdown of COVID-19	Telemedicine helped in Consultation without a physical visit, to appropriately triage the patients, who require an in-person visit, and timely referral.

S. No	Author (year)/ journal	Study Title	Study Population	Observations	Limitations	Conclusion
4	Gulati S et al (2021)/ Pediatric Nephrology[23]	Experience with telemedicine in pediatric nephrology during the COVID pandemic	n=90, Age 0.17-18 years	The distribution of the diagnoses was as follows: idio-pathic nephrotic syndrome (53), chronic kidney disease (17), kidney transplant (7), UTI (5), acute glomerulonephritis (4), acute kidney injury (2) and other (2). 87/90 were advised follow-up e-consults and 3 were advised admission. Based on teleconsultation, 3/90 (3.4%) of the children were successfully triaged into admission. 96.6% of OPD visits are avoided by teleconsultations.	Not mentioned the disease outcome	Telenephrology offered an effective method for providing pediatric nephrology services. It is also effective in providing individualized advice to this vulnerable segment of the population.

5 Raina R et al. Survey of n=400 Patients reported as equivalent In the physician survey, 7	
(2021)/ Telemedicine patients and quality and easier compared to there were no questions p	There is a lack of published trials in pediatric nephrology.

S. No	Author (year)/ journal	Study Title	Study Population	Observations	Limitations	Conclusion
6	Qiu Y et al. (2021)/ BMC health services research [25]	Adolescent and caregiver attitudes towards telemedicine use in pediatric nephrology	n=11 11.2- 18 years	The study population was 11- 18 years. Visit type preference was related to the nature of consultation and disease. For regular check-ups and less complex needs, telemedicine was comparable to an in- person visit. Patients with complex conditions preferred in-person visits.	Small sample size Study Conducted over the phone. No comments on disease outcome	Indiscriminate transfer to chronic care predicted on mainly telemedicine approach is not compatible with user- expressed attitudes.

The satisfaction level of patients receiving treatment should be assessed. There are studies, which assess patient satisfaction with telemedicine services; described in table 5.

S. No	Author(year)/jo urnal[ref]	Study Title	Study Population	Observations	Limitations	Conclusion
1	Paul PG et al (2006)/ Telemedicine Journal & e- Health [26]	Patient Satisfaction Levels During Teleophthalmology Consultation in Rural South India	n=348 18-83 years	44.4% reported- teleophthalmology screening was satisfactory. (95 percentile range [CI]: 38.58%-49.42%) Age, gender, education, and occupation, did not correlate with satisfaction levels.	They reported, their limitation as a lack of economic evaluation	The teleconsultation was very well received by patients. When questioned about the upcoming eye examination mode, teleophthalmology received an overwhelming response.

 Table 5:
 Studies on patient satisfaction with Telemedicine Services

S. No	Author(year)/jo urnal[ref]	Study Title	Study Population	Observations	Limitations	Conclusion
2	Kruse CS et al (2017)/ BMJ open [27]	Telehealth and patient satisfaction: a systematic review and narrative analysis	Out of 2193 articles after assessing for suitability 44 were assessed.	The elements that affect the effectiveness were reported. Improved outcomes (20%), preferred modality (10%), ease of use (9%), cheap cost (8%), improved communication (8%), and shorter travel time (7%), which together accounted for 61% of occurrences, were the factors most frequently mentioned.	Not clear whether the patient satisfaction observed was congruent with the change of intervention. Inferences that result from studies are difficult to generalize to conventional models.	This review identified a variety of factors of association between telehealth and patient satisfaction.

For assessment of satisfaction, with telemedicine services, there are various questionnaires. From the available literature, TUQ was the best and most used in recent studies to evaluate telemedicine services. It evaluates the usability of the system as a whole, with which the satisfaction of the patients is a subscale. Different questionnaires are available to assess the use and satisfaction with the services. The telemedicine Satisfaction Questionnaire (TSQ), Telemedicine Patient Questionnaire (TMPQ), and Telemedicine Satisfaction and Usefulness Questionnaire (TSUQ) were the most commonly used ones. Telemedicine questionnaires focus on three factors of usability: usefulness, satisfaction, and interaction quality between patient and clinician over telemedicine technology. TSQ is a questionnaire designed specifically for telemedicine systems. Telehealth services have become more systematic and software has also been developed for the same. With the evolution of the system there was a need for more components to be assessed, and so a need for a more comprehensive questionnaire that covers all usability factors (i.e., usefulness, ease of use, effectiveness, reliability, and satisfaction). With these objectives, a new questionnaire was developed. Table 6 describes studies on Questionnaires used in the assessment of patient satisfaction and usability of Telemedicine.

S. No	Author(year)/jo urnal[ref]	Study Title	Study Population	Observations	Limitations	Conclusion
1	Parmanto B et al (2016)/ International Journal of telerehabilitation [28]	Development of the Telehealth Usability Questionnaire (TUQ)	n=53 Age is not mentioned clearly	All of the TUQ's usability attributes were discovered to have good to outstanding dependability. Raw and consistent Cronbach's coefficient alpha values for each were indicative of the same.	This is a questionnaire, developed on the existing questionnaires, as technologies improve there is a need to modify or develop a new questionnaire	TUQ is a reliable, strong, and adaptable metric. It is built on the most effective usability tests available, able to address the most recent The TUQ will be useful for assessing usability given the growing prevalence of telehealth in the provision of clinical services remotely, as well as the development in the usage of computer-based systems that rely on software and a computer interface as the paradigm of delivering telehealth.

 Table 6: Studies on Questionnaires used in the assessment of patient satisfaction and usability of telemedicine

S. No	Author(year)/jo urnal[ref]	Study Title	Study Population	Observations	Limitations	Conclusion
2	Hajesmaeel- Gohari S et al (2021)/ BMC medical informatics and decision making [29]	The most used questionnaires for evaluating telemedicine services	53 articles were included in the study	Frequency of use of telehealth questionnaires: Telehealth Usability Questionnaire (TUQ) (19%), Telemedicine Satisfaction Questionnaire (TSQ) (13%), and Service User Technology Acceptability Questionnaire (SUTAQ) (5.5%).	Only the Pubmed database was used to search the articles. The search was restricted to the title and abstract fields.	A better evaluation is achieved by using questionnaires that have been specially created or by creating a new questionnaire that has fewer questions but is more thorough in terms of the concerns being investigated. Future improvements to telemedicine may be made by paying close attention to user requirements, end-user acceptability, and implementation procedures, as well as to users' satisfaction and usability testing.

TUQ is a standard questionnaire, which is used in assessing the usability of telemedicine. This questionnaire is used in assessing telemedicine services in multiple studies, which are described in table 7.

 Table 7: Studies that used TUQ for assessment of satisfaction and usability of Telemedicine

S. No.	Author(year)/j ournal[ref]	Study Title	Study Population	Observations	Limitations	Conclusions
1	Fung A et al (2020)/ Journal of clinical & translational endocrinology [30]	Evaluation of telephone and virtual visits for routine pediatric diabetes care during the COVID-19 pandemic	n=87 Mean age 12.8 years. SD-4.3	Visits made by phone and online received great usability ratings. 72% of participants want telehealth in the future.	Patients self-select- responder bias. There is a possibility that families with more technologically advanced diabetes care may have been more likely to respond to an email request for an online survey. The study didn't investigate the healthcare workers' views.	The usability of phone and online visits was excellent. Many families desire telehealth will be heavily involved in their future care.

S. No.	Author(year)/j ournal[ref]	Study Title	Study Population	Observations	Limitations	Conclusions
2	Layfield E et al (2020)/ Head & neck [31]	Telemedicine for head and neck ambulatory visits during COVID-19: Evaluating usability and patient satisfaction	n=100 Mean age=62.6 years SD -13.9 years	The overall average score for all questions was 6.01. The telehealth satisfaction questions received the highest marks (6.29), while The reliability questions received the lowest values (4.86).	Study in the setting of COVID- 19; a chance for a positive bias in satisfaction. Disease status was different, some with ongoing cancer, and some cured.	Patients are generally highly satisfied with telemedicine.
3	Cheng O et al (2020)/JAAOS Global Research &	Utilization of Telemedicine in Addressing Musculoskeletal	n=27	78.6% - medical explanations as outstanding, 92.9% - attending	Study in rural population Small sample size(n=27) Patients requiring Long term care	TeleMSK allowed for accessible, timely consultations without compromising the

Reviews [32]	Care Gap in	physician's care, skill,	quality of patient care.
Keviews [52]	_		quality of patient care.
	Long-Term Care	respect, and sensitivity	
	Patients	as excellent.	Most rated their
		85.7 % of Patients	experience as
		replied that their	excellent.
		confidence and Privacy	TeleMSK is an
		were protected and	excellent medium for
		maintained during the	long-term care in
		consultation.	chronic diseases.
		The majority of	
		telemedicine liaisons	
		agreed that TeleMSK	
		increased consultation	
		productivity and	
		accessibility.	
		81.5% strongly agreed	
		that they would utilize	
		TeleMSK again in the	
		future.	

S. No.	Author(year)/j ournal[ref]	Study Title	Study Population	Observations	Limitations	Conclusions
4	Waqar-Cowles LN et al (2021)/ Pediatric Rheumatology [33]	Evaluation of pediatric rheumatology telehealth satisfaction during the COVID-19 pandemic	n=248 n=27 (10.9%) >18 years, the rest less than 18 years.	JIA was the most common disease (33.5%). The median total TUQ score was 4 with positive responses in 81% of items. Usefulness scores were the lowest (median: 4, p < 0.001). Telehealth saves time traveling scored the highest median item score (median = 5, IQR: 4–5). Low scoring items: convenience, providing for needs, seeing rheumatologist as well as in person, and is an acceptable way to receive rheumatology services (all p < 0.001).	Technological reliability not assessed Patients without valid e-mail IDs were excluded. Study during the early period of COVID-19, when staff, caregivers, and patients were not trained well in using the system	Telehealth is a promising mode of healthcare delivery for pediatric rheumatic diseases but also identifies opportunities for improvement. Innovation and research are required to create a robust system

S. No.	Author(year)/j ournal[ref]	Study Title	Study Population	Observations	Limitations	Conclusions
5	Mostafa PI et al. (2022)/ Journal of Dermatological treatment[34]	Dermatological consultations in the COVID-19 era: Is teledermatology the key to social distancing? An Egyptian experience	n=70	The overall satisfaction and future use score received for Teledermatology services of 91.0%, a usefulness score of 93.7%, interface, and interaction quality scores of 85.9% and 87.0%, ease and use learnability score of 87.8%, and reliability score of 86.7%.	Satisfaction was assessed, just after the consultation, in the same setting. Scarce demographic data of Patients.	Teledermatology was efficient in triaging and treatment, decreasing the risk of COVID-19.

There are various methods for the assessment of Adherence to therapy. Adherence could be assessed, with the help of objective methods, which are more precise and there are questionnaires using measurements, where it is possible to identify the factors related to better or poor adherence. The various questionnaires were discussed in the study. 'Medication Adherence Measures: An Overview'' by Lam WY et al published in the Journal, BioMed research international., the various questionnaires available, and their advantages and disadvantages were discussed [11]. These questionnaires are described in table 8.

Table 8: Questionnaires for measuring adhe	erence
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Questionnaire and scales	Function(s)	Target population(s)	Advantages	Disadvantage(s)
Brief Medication Questionnaire	Patient's medication-taking behaviour Barriers to adherence	Diabetes Depression	Self-administration Evaluate multidrug regimes Reduce practitioner's training	Time-consuming
Hill-Bone Compliance Scale (Hill-Bone)	Patient's medication-taking behaviour Barriers to adherence	Hypertension-specific, black patients	High internal consistency in both primary and outpatient settings	Limited generalizability
8-item Morisky MedicationAdherence Scale (MMAS-8)	Patient's medication-taking behaviour Barriers to adherence	All validated conditions	Higher validity and reliability in patients with chronic diseases than in MAQ	

Medication Adherence Questionnaire (MAQ)	Barriers to adherence	All validated conditions	Quickest to administer Validated in the broadest range of diseases Validated in patients with low literacy	Comparatively short, mainly suitable for initial screening
The Self-Efficacy for Appropriate Medication Use Scale (SEAMS)	Barriers to adherence	All validated chronic conditions	High internal consistency in patients with high or low literacy	Time-consuming
Medication Adherence Report Scale (MARS)	Barriers to medication adherence Beliefs about medication adherence	Chronic mental illness, especially schizophrenia	Simplistic scoring Strong positive correlations compared to DAI and MAQ	Limited generalizability

For this study, as the study was during the Covid 19 Pandemic, we were not able to use objective methods for adherence measurement. We were having the option of the above-mentioned Questionnaires, but as this was a study in the pediatric population, we were in search of a questionnaire, that is validated in the pediatric population. A questionnaire was found for assessment of the adherence and associated factors in the study 'Factors associated to acceptable treatment adherence among children with chronic kidney disease in Guatemala' published in the journal PLOS ONE, in the year 2017. This Questionnaire was originally designed and validated in HIV patients in Spain and Peru. This questionnaire was adopted and validated in pediatric, HIV patients in Guatemala. After making relevant changes this was then adapted and validated in CKD children. Part of the questionnaire assesses adherence; this was used in our study. Adherence is important in the management of any disease as it affects the outcome of diseases. Some studies highlight the importance of adherence in various diseases, including renal diseases. Adherence is influenced by many factors, which are also evaluated in various studies; described in table 9.

Table 9: Studies on	patient adherence	to treatment.
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S. No	Author(year)/ journal	Study Title	Study Population	Observations	Limitations	Conclusions
1	Akchurin M et al (2014)/Clinica 1 Journal of the American Society of Nephrology[3 5]	Medication Adherence and Growth in Children with CKD	n=834 children	Children who were not following the rhGH did not see any change in height z score, but those who were following the rhGH experienced a significant improvement of 0.16 SDs (95% confidence interval, 0.05 to 0.27); the effect size was slightly bigger and remained significant after correction. Following adjustment, adherence to rhGH was linked to a 0.33 SD (95% confidence interval, 0.10 to 0.56) larger change in height z score among patients whose height was below the third percentile.	Even though the overall number was good enough, the patients in some of the drug groups were modest. Did not account for the severity of nonadherence (one who missed 5 drugs and one who missed 1 drug were considered in the same way.	Children with CKD whose self-reported nonadherence to rhGH was linked to a slower growth rate may be more amenable to treatment and have better outcomes.

S. No	Author(year)/ journal	Study Title	Study Population	Observations	Limitations	Conclusions
2	Ramay BM et al (2017) / PloS one[36]	Factors associated with acceptable treatment adherence among children with chronic kidney disease in Guatemala.	n=103/ Mean age 13.5 years (SD 3.16)	The average research population's adherence was 78% (SD 0.08; maximum: 96%; minimum: 55%). For transplant patients was 82% (SD 7.8, max 96%, min 63%), Dialysis patients: 76% (SD 7.8, max 90%, min 55%). The mother's educational level and higher monthly household income were both positively correlated with adherence.	This was a cross- sectional study The study used self- reported questionnaires.	Predisposing, enabling, and need variables all together highlight the difficulties in adherence in this population of children with CKD.

S. No	Author(year)/ journal	Study Title	Study Population	Observations	Limitations	Conclusions
3	Lippincott CK et al. (2022)/BMC infectious diseases [37]	Tuberculosis treatment adherence in the era of COVID- 19	n=52 Median age 43(iqr:30-57)	Pre-COVID and COVID periods' median verified adherence was generally similar (65% vs. 68%, p=0.96). The overall rate of adherence was considerably greater with video DOT (median 86% [IQR 70-98%]) than with DOT (median 59% [IQR 55- 64%], p0.01); this increased adherence with video DOT was noticeable in both the pre-COVID (median 98% vs 58%, p<0.01) and post- COVID period (median 80% vs. 62%, p=0.01).	Randomization was not done in the allocation of patients into 2 groups. The use of vDOT was influenced by COVID-19.	During the COVID period, video-DOT usage rose and proved to be more reliable than in- person DOT in confirming the consumption of prescribed medication.

Cost-benefit is expected to be better with telemedicine compared to in-person visits. In the study by Peter Trnka [12], described above there was a cost-benefit with telehealth was \$31,837 in 2013 (average saving of \$505 per consultation). In table 10, more studies analysing the cost and environmental benefits of telemedicine are described.

S. No	Author(year)/ journal	Study Title	Study Population	Observations	Limitations	Conclusions
1	Smith AC et al (2007)/ BMC health services research [38]	The costs and potential savings of a novel tele pediatric service in Queensland	n=1499 consultations	There was a cost- benefit of \$ 6 lakh with telepediatric services.	Cost analysis was done by estimating the cost provided for a group of patients and comparing it with the potential cost, which would have to be spent to send them to a tertiary care hospital. All the telepediatric consultations might not have avoided this travel	Telemedicine is cheaper compared to in-person visits.

Table No.10 Studies on cost analysis of telemedicine

S. No	Author(year)/ journal	Study Title	Study Population	Observations	Limitations	Conclusions
2	VersleijenM et al. (2015)/ Journal of Telemedicine and Telecare [39]	A telegeriatric service in a small rural hospital: A case study and cost analysis	n=208 /geriatric patients.	There was a saving of AUD\$131 per patient consultation with telegeriatric service.	There is no assessment of cost-benefit in terms of disease outcome.	Telegeriatric service offers an economically better approach to avail specialist geriatric care in rural and remote settings.
3	Snoswell CL et al. (2019)/ Journal of Telemedicine and Telecare [40]	A cost- consequence analysis comparing patient travel, outreach, and telehealth clinic models for a specialist diabetes service to Indigenous people in Queensland	Not reported	In this study, while comparing the cost to attend a telemedicine consultation, to the cost of travel to a metropolitan or outreach clinic, there was an economic benefit of approximately \$517.	The analysis was dependent on various assumptions associated with salary, travel, and accommodation costs, which have been outlined throughout	Even Though telehealth will not be able to completely replace in- person visits, even the replacement of some of the visits gives an economic advantage for the patient.

S. No	Author(year)/ journal	Study Title	Study Population	Observations	Limitations	Conclusions
4	Dullet NW et al (2017)/. Value in Health [41]	Impact of a University-Based Outpatient Telemedicine Program on Time Savings, Travel Costs, and Environmental Pollutants	19,246 consultations, in 11,281 patients	There was a savings of 5,345,602 miles. Savings of a total travel time savings of 4,708,891 minutes, almost 8.96 years Total travel cost savings of \$2,882,056. Environmental benefits of emissions savings of 1969 metric tons of CO 2, 50 metric tons of CO, 3.7 metric tons of NO <i>x</i> , and 5.5 metric tons of volatile organic compounds.	This was a retrospective study Other cost components, like saved working hours, wages, waiting time, and additional costs like parking.	Telemedicine has a positive impact on patients' travel time, travel cost, and environmental pollutants

LACUNAE IN LITERATURE

Telemedicine has been utilized for more than 3 decades. However, the system has never been a standard of care and has gained increasing popularity with the advent of the COVID -19 pandemic. It has been, a new service and almost all practitioners are using it with few guidelines at hand.

There is currently no data and audit on the quality of care and its impact on patient outcomes, satisfaction, and compliance. We intend to bridge some of this gap by prospectively studying a cohort of children seeking telemedicine consultations for renal problems.

RATIONALE

Research Question: Do telemedicine consultations affect the patient outcome, compliance, and satisfaction in pediatric Nephrology at AIIMS Jodhpur?

Hypothesis: Telemedicine affects patient satisfaction, compliance, and treatment outcomes in children seeking teleconsultation for pediatric renal problems

AIM AND OBJECTIVES

Primary Objective

To explore the outcome of the patients with renal disease attending the telemedicine service of the Pediatrics department of AIIMS Jodhpur.

Secondary objectives

- 1. To assess the satisfaction and compliance of patients taking teleconsultation in Pediatric Nephrology using a validated questionnaire.
- 2. To perform a cost analysis of the telemedicine service for Pediatric Nephrology patients using a predetermined questionnaire

MATERIAL AND METHODS

Ethics Approval

Institute's Ethics committee approval was obtained. [Certificate reference number AIIMS/IEC/2021/3312 dated 12/03/2021]

Study Design- Prospective cohort study

Study duration – Jan 2021 to December 2022.

Study place – Outpatient Department- Pediatric Nephrology clinic. Department of Pediatrics AIIMS Jodhpur.

Sample size- All consecutive patients who took teleconsultation for Pediatric Renal Problems were enrolled after obtaining Ethical Clearance from Jan 2021 to April 2022 followed by a 6-month follow-up for each patient enrolled.

Eligibility criteria:

Inclusion criteria:

1. Patients 29 days to 18 years of age who took telemedicine consultation for Renal related issues and are now on follow-up.

Exclusion criteria:

- 1. Patients with End-stage chronic kidney disease on dialysis.
- 2. Those seeking consult in a Pediatric Nephrology clinic but not seeking care for a renal problem.

Methodology

- Details of all the patients who met the inclusion criteria were obtained from the HIS on weekly basis and their primary details were recorded as per the proforma annexed.(Annexure-6)
- 2. At 1 month after their first telemedicine consultation (after enrolment into the study), Patients were followed up with a phone call, and satisfaction and compliance over the last month were assessed.
- 3. For obtaining patient satisfaction, the Telehealth Usability Questionnaire was used [28]. It is a validated Questionnaire that has six subscales (usefulness, ease of use and learnability, interface quality, interaction quality, reliability, and satisfaction and future use). There are different questions under each component. The answers to TUQ are based on a seven-point Likert scale. The total score was calculated. More the total score, the better the usability. Scores of independent questions were assessed and categorized as a positive response, negative response, or neutral response[score <4-Negative, 4- Neutral, >4- Positive]. The percentage of patients who have given positive scores for individual responses was calculated. Also, the mean score for individual responses and the Standard deviation and median score, and the range of scoring for individual responses were calculated(Annexure-7,8)
- 4. Compliance was assessed using a questionnaire previously used in patients with CKD [36]. The questionnaire identifies the overall level of adherence and associated factors for poor adherence. The questionnaire was administered telephonically to most patients or during in-person visits wherever feasible.

The questionnaire has 20 self-assessment questions with responses based on the Likert scale. It was originally based on a questionnaire designed and validated in HIV patients in Spain and Peru, addressing the psychosocial barriers, facilitators, and modulating factors associated with Compliance. Further, this questionnaire was adapted, applied, and validated in Pediatric, HIV patients in Guatemala. For adapting the questionnaire for use in this CKD Pediatric patient population in Guatemala, the research team reviewed the questions for relevance, and then validated the questions for comprehension. The

questionnaire was then validated in five patients with stage 4 CKD attending their clinic to determine comprehension, internal consistency, and duration of the questionnaire. The total score was 89. (Annexure- 9,10)

We extended the use of this questionnaire to all our renal patients.

Points scored for individual questions were summed up and this was expressed as a percentage. A higher percentage score was equated to better adherence.

Permission was taken from the respective authors of both questionnaires [Annexure - 11,12]. Questionnaires were translated into Hindi according to standard protocol. The original English questionnaire was initially translated to Hindi by 2 translators, after which the mismatches in both the translated versions were cleared and this was then back-translated to English by 2 different translators. These were then analysed by an expert committee. Discrepancies found were cleared and the final Hindi-translated version was made. A pilot run was done after which, the questionnaires were used on our patients without any modification.

- 5. Patients enrolled were assessed six months after the initial consultation to determine the disease-specific outcome. We scored each renal disease's clinical outcomes in terms of disease worsening, improving, or static at the end of six months. [Annexure-13]
- 6. Cost analysis was performed, using a predesigned questionnaire.

Cost analysis was done under the headings of cost for food for the patient, and transport of the patient. Cost for food and transport of the Attendants. Loss for the patient in terms of lost wages. The cost spent for the stay was also evaluated. Any other extra expenditure and any extra cost spent for internet services were also considered for cost analysis. Costs for drugs, investigations, and any hospital admission charges were also evaluated [Annexure - 14].

The average cost spent by the patient for in-person visits was determined. Any cost spent on telemedicine was also accounted for. The difference in cost spent for the patient fan or an in-person visit and telemedicine was calculated. This was the expected cost a patient would have saved with one telemedicine visit. This was multiplied by the number of telemedicine visits the patient had in the last 6 months, which gives us the financial benefit or burden for a patient with telemedicine. The total cost saved by all the patients was determined.

Data was collected on telephone calls. One month after enrolling in the study, the TUQ and Adherence questionnaire were administered. Data of some patients were collected with multiple phone calls. After 6 months, patients were followed up with a Phone call, for cost analysis, as per the prepared questionnaire. Disease-specific outcomes were also assessed, by asking about their current symptoms, any worsening,(scores given as per Annexure -13), and whether it could be a result of a lack of physical consultation.

Flow chart of study:

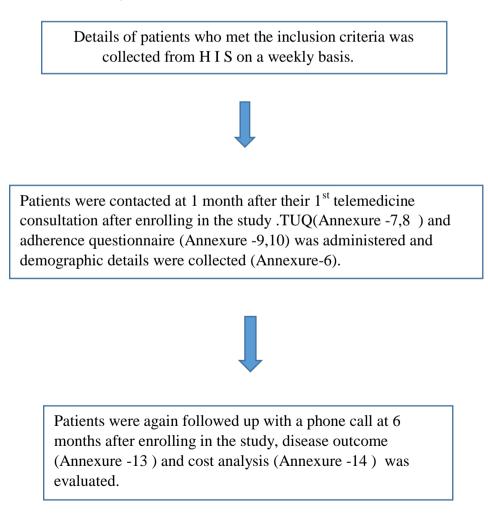


Figure 1, represents a prescription after a telemedicine consultation, which is available for the patient on the online patient portal.

Fig No.1	Prescription	after a	telemedicine	consultation.
I 15 I 101I	I I Coci iption	uiter u	continuation	compartation

History/Examination :	Relapse on MMF- steroids full done 35 mg started since 19/ 03/2021, Currently patient is on MMF 250 mg bd (since 21/1/21), tacrolimus stopped on 1/2/21,
Treatment/Progress :	Currently, urine protein trace since 26/03/2021, and shifted to 35 mg EOD since 29/03/2021. However recurrence of 3+ proteinuria since 09/04/2021no edema , BP – not done , WT 17 kgs . on MMF, envas and calcium supplementation.
Remarks :	1) Tab MMF 500 mg – 250 po bd (increased dose today) 2)Tab prednisolone 35 mg po OD till urine protein trace/ negative for 3 consequtive days (max 28 days) followed by 25 mg EOD for 1 month followed by tapering. 3) tab Envas 2.5 mg OD at night 4) tab shelcal 500 mg po od daily 5) urine protein ,BP and weight monitoring danger signs explained review for iv cycopphsphamide in case of no remission
Next Follow up Date :	20-04-2021 11:30 AM
ध्यान	दें : दवा सेवन के पश्चात यदि कछ भी असामन्य लगे तो चिकित्सक को अवश्य बतायें।

Summary of telemedicine workflow of our hospital

The telemedicine services of our hospital are by means of a direct landline for Phone calls. Any media exchange is done using the WhatsApp business feature, installed; with a hospital-provided mobile number. This number is also often used by patients to directly contact their physician's team in an emergency or when the appointment is unavailable. It therefore also becomes another official telemedicine consult. The H I S was used to obtain previous medical records, and investigations, and for the patient to get a medical record of their consultation, and the medicine prescription After getting the appointment, the doctor could see the patient list from the HIS. Patients are contacted telephonically and teleconsultation was provided after a complete assessment of their disease condition by the team of consulting pediatric Nephrologists. Note of each visit was maintained in the H I S. The patient could access his or her prescription by logging into the H I S. The prescription was also sent using WhatsApp to all patients for easing their access to it.

Statistical Analysis

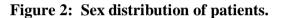
All the data were entered in the Excel sheet, 2010, and statistical analysis was performed using the statistical software STATA 14. Qualitative data was represented in the form of frequency, percentage median values (IQR), and mean (standard deviation). The Shaperowilk test was used to assess normality. The correlation of dependent variables with independent variables was done by assessing Spearman's correlation coefficient.

OBSERVATIONS AND RESULTS

This prospective cohort study was conducted at AIIMS Jodhpur, a tertiary care centre in western Rajasthan. The study was conducted over 1 year and 7 months [16/03/2021-12/10/2022]. The baseline demographic characteristics of the study population were as follows.

Demographic Characteristics.

112 Patients were enrolled. The median age was 8 years(4-13). 66.1%(n=74) males and 33.9 %(n=38) were females. Represented pictorially in figure 2.



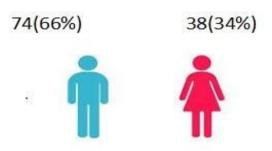


 Table 11: Frequency distribution as per age category

Age Group	Number of Patients
1 month-3 years	26
4 -6 years	21
7-9 years	22
10-12 years	13
13-15 years	16
16-18 years	14

Telemedicine consultations were attended by the Father, mother, siblings, uncles, and grandparents of our patients. In majority, attended by Father.

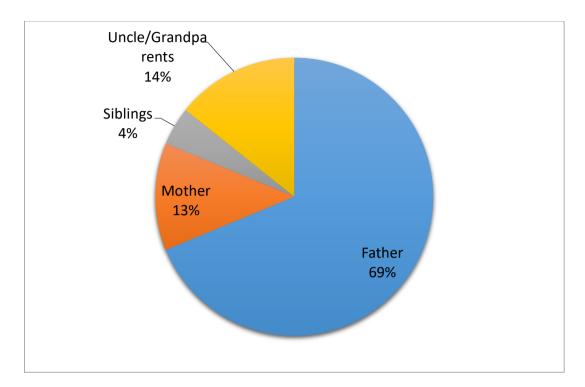


Figure 3: Person attending teleconsultation.

40 % (n=45) were from nuclear family and 60% (n=67) from joint family. This is represented by the pie chart in figure 4.

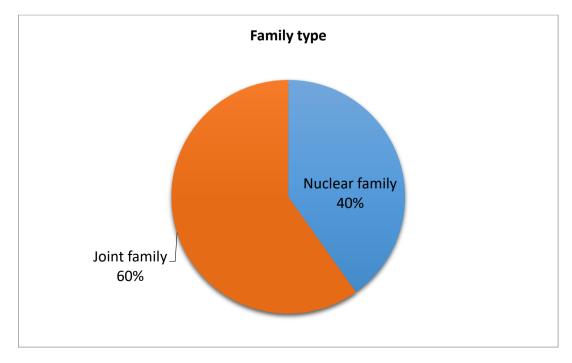


Figure 4: Family Type.

Many of the patients(65%) had an idea about telemedicine.

Frequency distribution Educational Qualifications of the Head of the family are given in table 12.

Educational Qualification	Number
Profession of Honours	5
Graduate	36
Intermediate or Diploma	14
High school	20
Middle School	11
Primary School	11
Illiterate	15

 Table 12: Educational qualification of the head of the family

Our patients' median family income per year was 2 Lakh(1-4). Table 13 represents the frequency distribution of the family income, classified as per the Modified Kuppuswamy scale 2022.

Table 13:Family income.

Monthly Family Income	Number
>/= 1,84,376	0
92,191-1,84,370	4
68,967-92185	2
46,095-68,961	10
27,654-46,089	18
9,232-27,648	43
=9226</td <td>35</td>	35

The educational qualification of the one attending the telemedicine was classified according to the scale used in the Modified Kuppuswamy scale. Figure 5 represents the frequency distribution of the educational qualification of the one attending teleconsultations.

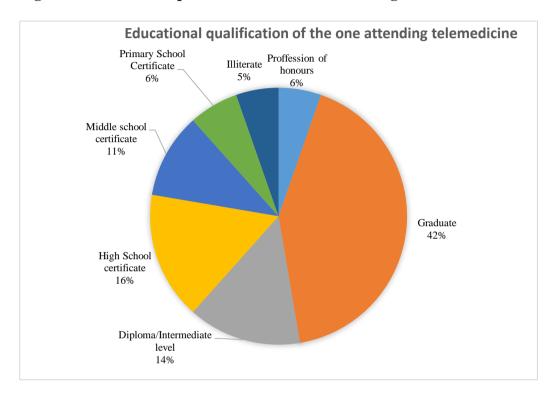


Figure 5: Educational qualification of the one attending telemedicine.

We had patients from different districts of Rajasthan. In figure 6 this district-wise distribution is plotted on the graph of Rajasthan.

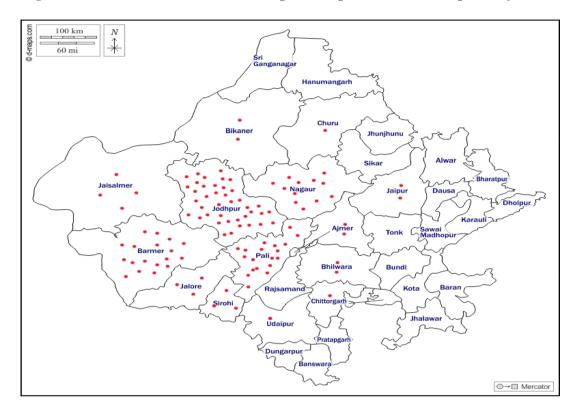


Figure 6: District-wise distribution of patients plotted on the map of Rajasthan.

The frequency distribution of patients from different districts is represented in Table 14.

District	No of patients
Jodhpur	40(35.7%)
Pali	19(17%)
Barmer	18(16%)
Nagaur	12(10%)
Jaisalmer	4(3.5%)
Jalore	3(2.5%)
Sirohi	3(2.5%)
Ajmer	2(2%)
Bhilwara	2(2%)
Bikaner	2(2%)
Jaipur	2(2%)
Chittorgarh	1(1%)
Churu	1(1%)
Udaipur	1(1%)

Table 14: District-wise distribution of patients

We also had 2 patients from outside Rajasthan

Table 15: Residence outside Rajasthan

District	No of patients
Gurgaon (Haryana)	1
Una(Himachal Pradesh)	1

The median distance from residence to AIIMS Jodhpur was 122.5 Km(30-250).

Our patients have saved a travel distance of 83274 Km in the six months.

Average 743 km per patient in the 6 months. We have collected the distance from our institute to the home of each patient. When this was multiplied by 2, we get the distance of a round trip. The number of telemedicine visits was not the same for all the patients. So the distance of the round trip was multiplied by the number of visits of the respective patients. These were added and we got a figure of 83274 km.

F		
Distance travelled by	N [n1,n2n112]	Mean =147 km
individual patients		[Median=122.5
from home to AIIMS.		Km (IQR:30-
		250]
Distance on each	2N	
round trip		
Number of	X [x1,x2x112]	Median
telemedicine visits of		telemedicine
each patient in 6		visits 2 (IQR:1-
months		4)
Distance travel saved	2NX	Mean=743 Km.
by each patient in 6		[Median=360
months.		Km,(IQR:80-
		1012.5)]
Total Distance saved	2NX[2n1x1+2n2x2+2n3x32n112x112]	83274 km

Table 16: Calculation of distance saved

A basic understanding of the attendants regarding telemedicine is represented in Figure 7.

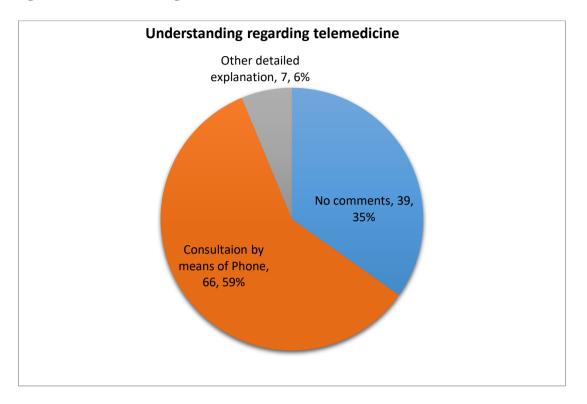


Figure 7: Understanding of telemedicine.

All of the patients had an access to smartphones; the basic need for our Telemedicine service. For getting an appointment for telemedicine consultation, 32% (n=36) got their service done from AIIMS during their Physical visits, 34% (n=38) did it by themselves, 27 %(n=30) got an appointment through E Mitra (Local computer centres).7%(n=8) got it done with the help of relatives or friends. This is depicted in figure 8.

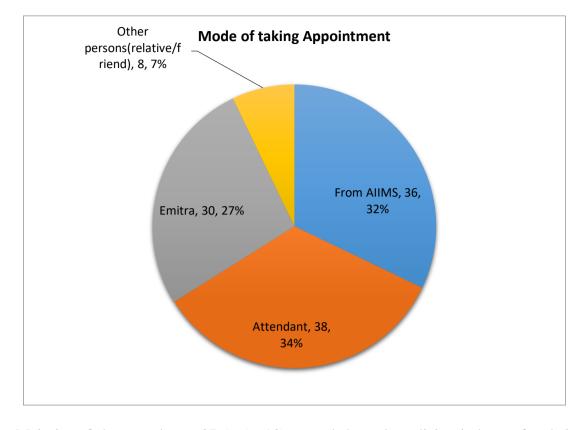


Figure 8: Mode of taking appointment.

Majority of the attendants -87.5%(n=98) agreed that telemedicine is better for their child. When enquired about their Preferred mode of consultation, the majority 40% (n=45) preferred telemedicine. This is depicted in figure 9.

Many of our patients had experience with teleconsultation prior to enrolling in the thesis. We also assessed the number of teleconsultations prior to the administration of TUQ the and adherence questionnaire by adding the number of teleconsultations prior to enrolment and teleconsultation in the one-month period.

The **median** number of telemedicine consultations prior to administration of TUQ and adherence questionnaire **was 2(IQR:1-6**)

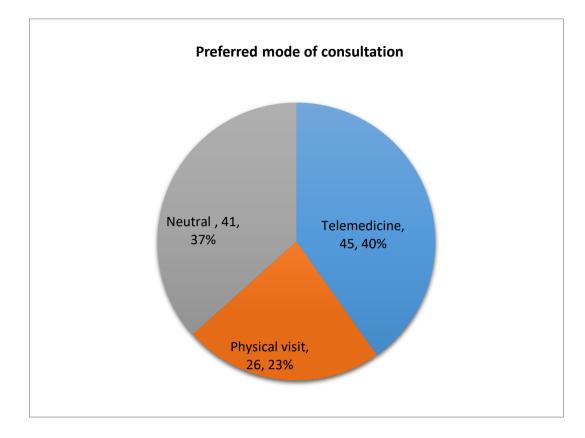


Figure 9: Preferred mode of consultation.

34 patients had telemedicine visits only during the 6 months. The median telemedicine visit was 2 (IQR:1-4). There was a requirement of physical visits for 75 people, with a median visit of 1. Out of the physical visit, 17 - Investigations, 9- Routine Follow up, 32-Both investigations and Routine follow up,12- Disease worsening,5-non Renal related disease related visits.

Figure 10 represents the frequency distribution of Diagnosis at enrolment.

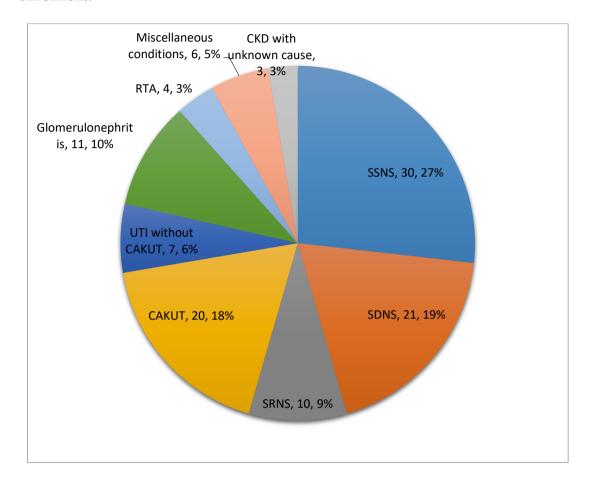


Figure 10: Case distribution at the time of the first telemedicine consultation after enrolment.

Other six diseases were 1 Hypercalciuria under evaluation, one each of Atypical Haemolytic Uremic Syndrome, Familial hypercalciuria with CKD stage 4, Renal artery stenosis with hypertension stage 2, Nocturnal enuresis, and haematuria under evaluation.

3 patients with SDNS,6 SRNS,7 CAKUT, 3 CKD with unknown cause, and 1 SLE, had stage 2 Hypertension.

One patient with CAKUT was having stage 1 Hypertension.

Outcome and Follow up at 6 months

The Median telemedicine visits over the 6 months were 2 (IQR:1-4). The Median inperson visits of our patients were 1 (IQR:0-2). There was a requirement of Hospital admission for 15 patients.

Out of this 6 was emergency admission, due to complication. In four patients the previous visit was telemedicine. Scoring was done as per the proforma annexed.

There was a worsening of disease condition in 21 patients with 1 death.

Score 1 for 88, 20 with a score of 2, and 1 patient with a disease outcome score of 3. (Annexure-13) Score 1 represented, resolved, or disease under control. Other higher scores according to the worsening severity of the disease. While considering the outcome, 3 patients who were lost to follow-up were not considered, Patients who discontinued follow-up were also assessed, as they had telemedicine visits with us, and their outcome was also documented. The overall disease outcome score is depicted in

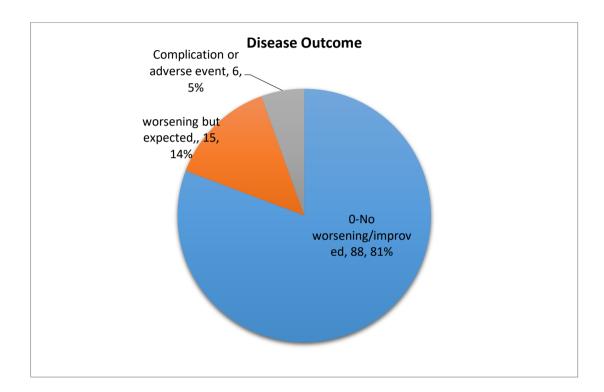
table 19.

Table 17: Overall Disease Outcome score [as per the scoring annexed (annexure-13)]

Score 1	88
Score 2	20
Score 3	1

Disease outcome in terms of whether, the disease is resolved or under control, any worsening – was it expected or was it an adverse event(3 categories) is depicted in figure 11.

Figure 11: Disease outcome in terms of whether the disease was resolved or under control /any worsening -was it expected or was it an adverse event or complication (3 categories)



The following tables (Table 18-26) represent the distribution of disease course of individual illnesses with telemedicine follow-up at 6 months.

Patient with multiple diseases was given baseline scores of 1 when the disease was under control, scoring was hiked according to the disease. We had patients with hypertension superadded with other diseases, while scoring, if there was a worsening of hypertension, the scoring was hiked as per the proforma annexed (annexure -13). But if every disease was under control the score was 1.

 Table 18: Disease Outcome in Steroid sensitive nephrotic Syndrome

Outcome Score [remission (1),	No of Patients
progression(+1), drug toxicity(+1),	
complication(+1)]	
Score 1	25
Score 2	3
Score 3	0

Table 19: Disease Outcome in Steroid Dependent nephrotic Syndrome

Outcome Score [remission (1),	No of Patients
progression(+1), drug toxicity(+1),	
complication(+1)]	
Score 1	12
Score 2	9
Score 3	0

Table 20: Disease outcome in Steroid resistant nephrotic syndrome

Outcome Score [remission (1),	No of Patients
progression(+1), drug toxicity(+1),	
complication(+1)]	
Score 1	6
Score 2	3
Score 3	1

Table 21: Disease outcome in Glomerulonephritis

Outcome Score [remission (1),	No of Patients
progression(+1), drug toxicity(+1),	
complication(+1)]	
Score 1	11
Score 2	0
Score 3	0

Table 22: Disease outcome in CAKUT

Outcome Score [static(1), complication	No of Patients
including acute decompensation/UTI	
(+1), progression to CKD(+1)	
Score 1	18
Score 2	1
Score 3	0

Table 23: Disease outcome in CKD with unknown cause

Outcome Score	No of Patients
[stable(1),progression(+1), acute	
decompensation(+1)]	
Score 1	1
Score 2	2
Score 3	0

In one CKD patient there was one episode of hypertensive urgency and so was given a score of 2. The kidney function of the patient was not worsening.

Table 24: Disease outcome in Renal tubular acidosis.

Outcome Score [Growth adequate (1),	No of Patients
growth inadequate (+1)]	
Score 1	3
Score 2	1
Score 3	0

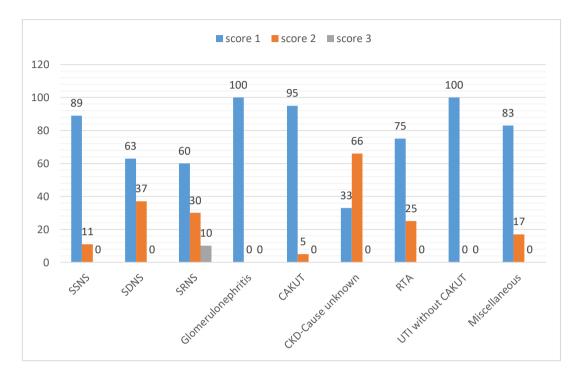
Table 25: Disease outcome in UTI without CAKUT

Outcome Score[No further UTI (1),	No of Patients
Recurrent UTI (+1)]	
Score 1	7
Score 2	0
Score 3	0

Table 26: Disease outcome in Miscellaneous conditions

Outcome Score[Static course (1), Single	No of Patients
complication(+1), multiple	
complication(+2)]	
Score 1	5
Score 2	1
Score 3	0

Figure 12: Graphical representation of outcome score in different diseases (expressed as a percentage of patients with a specific score in respective diseases)



Out of these patients, at 6 months, were not able to follow up 3 patients.14 patients were not continuing treatment in AIIMS. Out of these 14 patients,4 attendants did not disclose the reason, 2 stopped treatment due to personal reasons, 6 attendants believed that the patient is disease free, and 2 attendants replied that they were having difficulties with the telemedicine service. patients did not disclose the reason

Satisfaction and usability of telemedicine service

Our telemedicine service's usability was assessed using the standard questionnaire – Telemedicine usability questionnaire; satisfaction is a subscale of the Questionnaire. The response was in the form of a Likert scale. Score 4 being neutral. Scores above 4 are positive response responses who gave positive responses for each component were assessed.

1 Telehealth improves my access to healthcare services. 84.82 (n=95) 2 Telehealth improves my access to healthcare services. 100 (n=112) 3 Telehealth provides for my healthcare need. 86.61 (n=97) 4 It was simple to use this system. 98.2 (n=110) 5 It was easy to learn to use the system. 98.2 (n=110) 6 I believe I could become productive quickly using this system 83 (n=93) 7 The way I interact with this system is pleasant. 95.54 (n=10) 8 I like using the system. 86.61 (n=97) 9 The system is simple and easy to understand. 98.2 (n=109) 10 This system can do everything I would want it to be able to do. 83.4 (n=93) 11 I can easily talk to the clinician using the telehealth system. 99.1 (n=111) 12 I can hear the clinician clearly telehealth system. 99.1 (n=111) 13 I felt I was able to express myself effectively. 88.39 (n=90) 14 Using the telehealth system, I can see the clinician as well as if we met in person visits. 67.86 (n=76) 15 I think the visits provided over the telehealth system are the same as inperson visits. 0 16 Whenev	Sl	Statements	Percentage
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17 The system gave error messages that clearly how to fix problems. 0 18 I feel comfortable communicating with the clinician using the telehealth system. 89.29 (n=100) 19 Telehealth is an acceptable way to receive healthcare services. 87.5 (n=98) 20 I would use telehealth services again. 88.39 (n=99)	16	Whenever I made a mistake using the system, I could recover easily	1.79 (n=2)
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19Telehealth is an acceptable way to receive healthcare services.87.5 (n=98)20I would use telehealth services again.88.39 (n=99)	18	I feel comfortable communicating with the clinician using the	89.29 (n=100)
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	19	Telehealth is an acceptable way to receive healthcare services.	87.5 (n=98)
21 Overall Lam satisfied with this telehealth system $97.5 (n-00)$	20	I would use telehealth services again.	88.39 (n=99)
$\begin{bmatrix} 21 & 0 \text{ votall, 1 all sausticu with this teleficiditi system.} \\ 87.3 (II=98) \end{bmatrix}$	21	Overall, I am satisfied with this telehealth system.	87.5 (n=98)

Table 27: Positive response in Telehealth Usability Questionnaire (TUQ)

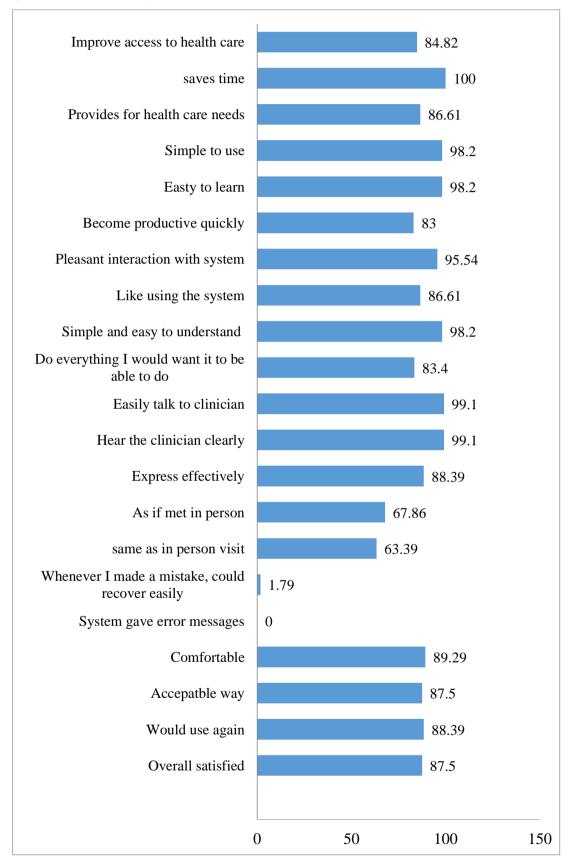


Figure 13: Graphic depiction of positive response in Telehealth Usability Questionnaire (TUQ)

Individual Components of the least scored subscale- Reliability. Figure 14-17 depicts the frequency distribution of response for individual subscale reliability.

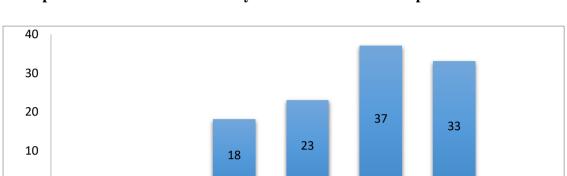


Figure 14: Graphic depiction of response to individual component- 'I think the visits provided over the telehealth system are the same as in-person visits.'

Figure 15: Graphic depiction of response to individual component- 'Whenever I made a mistake using the system, I could recover easily and quickly'.

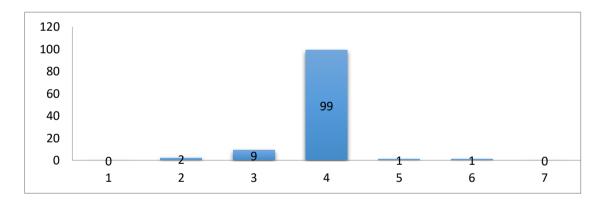


Figure 16: Graphic depiction of response to individual component- 'The system gave error messages that clearly how to fix problems'.

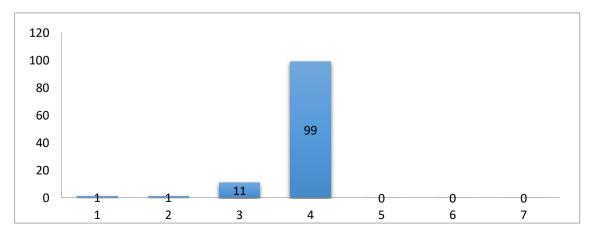


Figure 17 depicts the percentage of positive responses, scored in different subscales of TUQ.

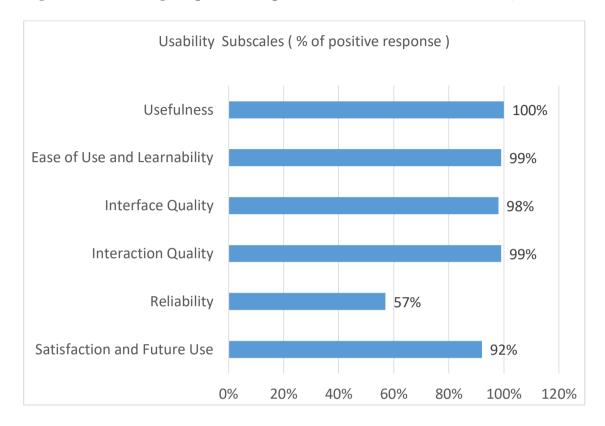


Figure 17: Percentage of positive response in different subscales of TUQ.

Sl	Statements	Median
No.		(IQR)
1	Telehealth improves my access to healthcare services.	6(5-6)
2	Telehealth saves me time traveling to a hospital or specialist clinic.	
3	Telehealth provides for my healthcare need.	6(5-6)
4	It was simple to use this system.	6(6-6)
5	It was easy to learn to use the system.	6(6-6)
6	I believe I could become productive quickly using this system	6(5-6)
7	The way I interact with this system is pleasant.	6(6-6)
8	I like using the system.	6(6-6)
9	The system is simple and easy to understand.	6(6-6)
10	This system can do everything I would want it to be able to do.	6(5-6)
11	I can easily talk to the clinician using the telehealth system.	6(6-7)
12	I can hear the clinician clearly telehealth system.	6(6-7)
13	I felt I was able to express myself effectively.	6(5-6)
14	Using the telehealth system, I can see the clinician as well as if we met in person.	5(4-6)
15	I think the visits provided over the telehealth system are the same as in-person visits.	5(4-6)
16	Whenever I made a mistake using the system, I could recover easily and quickly.	4(4-4)
17	The system gave error messages that clearly how to fix problems.	4(4-4)
18	I feel comfortable communicating with the clinician using the telehealth system.	6(5.5-6)
19	Telehealth is an acceptable way to receive healthcare services.	6(5.5-6)
20	I would use telehealth services again.	6(5.5-6)
21	Overall, I am satisfied with this telehealth system.	6(5.5-6)

Table 28: Response to individual components of TUQ expressed as median(IQR)

Adherence to Treatment

Adherence was assessed by administering an adherence questionnaire. Individual component scores were

Table 29: Table with responses to the Adherence questionnaire expressed as mean.

	Question	Likert scale range of responses	Mean (±SD)
1	If at any moment you observed the patient feeling sad, did you stop giving them the medication (or did they stop taking the medication)?	Always=1, Never=5	4.99(0.095)
2	If at any moment the patient felt sick, did you stop giving the patient their medication (or did they stop taking the medication)?	Always=1, Never=5	4.99(0.094)
3	Do you feel capable le supporting the patient in taking their medication to treat their illness (or do you feel capable of taking medication for your illness)?	Not at all=1, Very much=5	4.98(0.133)
4	If at any moment you observed the patient feeling better, did you stop giving the patient their medication (or did they stop taking the medication)?	Always=1, Never=5	4.92(0.447)
5	Has the patient stopped taking their medication at any time?	Always=1, Never=5	4.91(0.476)
6	How would you rate the relationship you have with the doctor and the health care team?	Poor=1, Excellent=5	4.96(0.186)
7	Do you give the patient the medications at the same time every day (or does the patient take their medication at the same time every day)?	Never=1, Always=5	4.77(0.424)
8	In your opinion, how beneficial is taking these medications?	Not at all=1, Very much=5	4.79(0.454)
9	Do you consider yourself adherent to the patient's medication therapy (or your medication therapy)?	Never=1, Always=5	4.91(0.369)

10	In general, how happy are you (and the patient)	Unsatisfied=1,	4.29(0.731)
10	since the patient started taking their medication?	Satisfied= 5	4.29(0.731)
11	How do you rate the intensity of the side effects experienced related to these medications?	Very intense=1, Not intense at all=5	4.42(0.639)
12	When you receive good news about the progress of your disease does your doctor use the news to encourage you to continue taking your medication?	Never=1, Always=5	4.96(0.207)
13	How much time do you spend taking medications?	A lot=1, Not much=5	4.96(0.243)
14	Do you think that the patient's health has improved since you started giving them medication?	Not at all=1, Very much=5	4.79(0.492)
15	How difficult do you perceive taking medication?	Very hard=1, Not hard at all=5	4.91(0.286)
16	Do you think you have a sufficient amount of information regarding the medication the patient uses?	Insufficient=1, More than enough=5	3.86(0.868)
17	How hard is it for you to maintain your treatment adherence, and come to your appointments?	Very hard=1, Not hard at all=5	4.85(0.385)
18	Of all of the medications you take, how many do you take all the time?	None=0, All=2	1.97(0.163)
19	Since the patient began medication therapy, have they ever missed a complete day of taking their medications?	yes=0, no=1	0.93(0.259)
20	Do you or the patient use any sort of strategy to remember to take their medications?	yes=0, no=1	0.84(0.369)
	Total Score		84.87(4.07)

The median adherence score was 86(IQR-83-88) out of a total score of 89. Among individual components, **knowledge about medication** scored the least, with a mean score of 3.85.

Cost Analysis

Cost Analysis was done by assessing the difference between the expenditure for an inperson visit, and the expenditure for a telemedicine consultation. All the patients had more expenditure for an in-person visit. Loss of wages was also assessed, for attending consultations.

15 %(n=17) of Patients required overnight stay, out of which, 10 Patients spent on renting a room, while 7 stayed at relatives' houses.

For an in-person visit, all the patients spent money on transportation including the patients (only 29% had an expenditure for patients' transportation – others were not charged as their age was less) and the attendants.

40% didn't have any expenditure on patients' food

The median expenditure for food and transport of outpatients was INR 100(IQR:0-300) per The average expenditure of INR 180.

The median expenditure for transport and food of attendants per visit was 450(IQR,100-1000), with an average expenditure of INR 830.

There was a loss of work for 75 attendants. There was a loss of wages for the attendants of 47 patients. The rest were having paid leaves. The median loss of wages was INR 300(IQR:0-500). The average loss as lost wages was INR 330.

The median expenditure for one in-person visit was INR 810(IQR:310-1410). Considering the lost wages, for a straight visit there was a median loss of INR 1110(IQR:610-1810)

Table 30: Expenditure in a single visit

	Cost for Cost for food		Cost for	The	Lost	Expenditure
food and		and transport	Transport	cost	Wages	for a single
transport		of Attendants	in the case	spent	for a	in-person
of Patients		for a single	where	for the	single	visit
for a		visit(not	they used	stay	visit	(including
	single	including the	Taxi or			lost wages)
	visit	cost of private	private			
		transport or	transport.			
		taxi)				
Mean	180	850	152	53*	330	1577
Median	100	450	-	-	300	1110
Total	19535	92775	16550	5800	36200	171940

Cost in INR

[*This varied if the mode of transport was a taxi or a private transport.[n=26]. <u>The</u> total cost in this category was INR 16550, with an average of INR 152/patient.

Note: OPD ticket charge was another expense for a straight visit.[Rs. 10/-].

Only 4 patients had to spend extra on the internet for telemedicine services. Some patients had to depend on the E Mitra service, and there was an extra expenditure for this service. None of the attendants had any loss of wages or any extra cost for travel to avail of the Telemedicine service. Expenditure for availing telemedicine was calculated in total for the six months, as the expenditure for a single telemedicine visit was variable.

Table 33 depicts the mode of getting an appointment

Table 31: Mode of Getting Appointment

Mode of getting an appointment	Number of Patients
Directly from AIIMS	36
An attendant from his phone/computer	38
E Mitra	30
Done by a relative/friend	8

The median Expenditure for Telemedicine services over 6 month period was INR 30(IQR:0-50).

There was a total saving of **INR 4,57,900** considering all the patients.

The cost spent for a single visit(x) was calculated, which included the cost of food and transport of the patients and attendants, stay, OP ticket charge, and lost wages. This represents the expenditure for a single straight visit. The number of telemedicine visit for all the patients were not equal and so their benefit from telemedicine. We then multiplied the respective expenditure for a single visit by the number of their telemedicine visits in six months. (xy)

Expenditure of telemedicine differs with each visit, so the total expenditure for 6 months for every patient was assessed(z).

xy-z, savings of the respective patients in 6 months period.

To get the percentage saving, the family income of one year was divided by 2, so that we got the income over 6 months. The saving of individual patients over 6 months was then divided with their family income over 6 months, which gave their percentage savings.

This was then summed up, which gave the total savings in 6 months= of 4,57,900

The cost is spent	Х	The average saving per visit	Rs. 1577/patient /visit
on a single in-			
person visit.			
Telemedicine	У	Average Saving per patient	Rs. 4200 [Median -2130
visits in 6		over 6 months	(IQR 820-4390)
months			
Expenditure for	Z	Family Income /annum	Mean=2.97 Lakh.
telemedicine			Median=2 Lakh(IQR:1-4
visit in 6 months			Lakh)
(z)			
Saving for each	xy-z	Saving on health per family	Mean-
patient		with respect to family income	4.99%.Range(0.012-37%)
			[Median -2.16 %(IQR :
			0.66-5.5]
Total savings on	$(xy-z)_1+$		
telemedicine for	(xy-z) ₂ +		
all patients	(xy-z) ₃		
	(xy-z) ₁₁₂		
Figure in INR	457900		

Table 32: Calculation of cost saving

Average cost saving of INR -1577/patient/visit.

There were 266 telemedicine visits during the study period.

INR 4200 was the average saving over the six months per patient.

Median of 2130(820-4390)

Estimated: Mean savings was 4.99% of the family income[Range:0.012%-37%], a median of 2.16 % [IQR:0.66-5,55%] per patient over the 6 months.

We could find a correlation between total number of telemedicine consultations prior to the administration of TUQ and the total TUQ score, with a spearman's coefficient of **0.295** with a p value **0.0016**.

The various demographic factors, like sex of the patient, age of the patient, distance from home to AIIMS, jodhpur, educational status of the one attending the telemedicine, and Family type to which the child belongs, were analysed to see for any correlation with total TUQ score. But couldn't find any statistically significant correlation.

The correlation between demographic characteristics and Adherence was not calculated as the adherence was skewed to the higher side.

DISCUSSION

Even though telemedicine was in use from the beginning of 19 the century [2], it has only found its footing during the COVID times. Taking this as an opportunity to assess telemedicine, we started the study. There needs to be more data assessing the utility of telemedicine, in pediatric nephrology, in terms of disease outcome, satisfaction, and adherence.

One hundred twelve patients were enrolled; the majority were males (66%). More patients 23 %(n=26) were in the age group of 1 month to 3 years.[42 % were less than 6 years].The caregivers who sought teleconsult primarily included the father(69%), the mother(13%), uncles or grandparents(14%), and in 4%, siblings. Only 5% were illiterate;42 % were graduates. The literacy status of parents was assessed, and we found that the fathers of most patients were literate, $\frac{1}{3}$ rd (n=36) were graduates, and only 13.4 %(n=15) were illiterate.

Case Profile

The majority of cases were of Nephrotic Syndrome-55%.Followed by CKD at 21 %, CAKUT-18%, glomerulonephritis -at 10%, UTI without CAKUT-6%, RTA at 3%, CKD with unknown cause at 3%, and other miscellaneous conditions -at 5%.(Which included 1 of Hypercalciuria under evaluation, one each of Familial hypercalciuria with nephrocalcinosis with CKD, Atypical Haemolytic Uremic Syndrome, Renal artery stenosis with hypertension, nocturnal enuresis, and hematuria under evaluation)

Compared to other studies done in pediatric nephrology, in the study done by Peter Trnka, the case distribution was CAKUT; the largest group of renal diseases (30 %) involved in telehealth consultations, followed by nephrotic syndrome (16 %), kidney transplant (12 %), and urinary tract infection (9 %), along with proteinuria, acute kidney injury, renal tubular acidosis, diabetes insipidus, and syndromes (Bardet-Biedl, Denys-Drash, Williams, prune belly) [12]. (as described in Table 4, sl no 2)

We didn't have any renal transplant patients.

Only two patients were from outside Rajasthan. The majority of the patients were from Jodhpur District, 35.7 %(n=40), 17 %(n=19) from Pali, 16% (n=18) from Barmer,

and 10 % (n=12) from Nagaur, which are the neighbouring districts. The majority (60%) were from joint families.

The median distance from residence to AIIMS Jodhpur was **122.5 Km**(IQR:30-250). As the number of telemedicine increased, the saved distance was more. Our patients have saved a travel distance of 83274 Km in the six months. Average **743 km** per patient in the 6 months. This is a significant benefit for the patient.

In the study by Yi Qui, the median distance to their tertiary centre was 191 km (range 110–1378 km). The median travelling distance saved by using telemedicine was 190 km (range 88-1377 km) one way per visit [25]. (as described in table 4, sl no 6)

In another study, a retrospective analysis of 19,246 consultations among 11,281 unique patients. With telemedicine, total travel distance savings of (8602912.505 km), 4,708,891 minutes of total travel time savings (8.96 years), and a total direct travel cost savings of \$ 2,882,056. The mean distance savings per consultation were 278 miles(447 km), the average travel time savings were 245 minutes, and the average cost savings were \$156. Environmental benefits with a total emissions savings of 1969 metric tons of CO 2, 50 metric tons of CO, 3.7 metric tons of NO *x*, and 5.5 metric tons of volatile organic compounds.[41](as described in table 10, sl no 4)

In our study, the travel distance saved per visit was 313 km, a little less compared to this study, but this is expected as the geographical condition is different in these 2 countries. Most of the patients were using public transport, so it was not possible to calculate fuel requirements and so not able to calculate environmental benefits.

When we assessed the basic understanding regarding Telemedicine, among the ones attending telemedicine consultation, we found that 6% had a good understanding, 59% had an idea about the system, and the rest were unaware.

For getting an appointment for telemedicine consultation, 32 % (n=36) got their service done from AIIMS during their Physical visits, 34%(n=38) did it by themselves, 27 %(n=30) got an appointment through E Mitra (Local computer centres).7%(n=8) got it done with the help of relatives or friends. This indicates that only one-third of patients can use the benefit of the service to its full effect. But even though 27 % of patients had to depend on E Mitra for appointments, none of them had

any extra expenditure for travel or loss of job. But they had to pay extra, an average of Rs 30 in excess of, those who were able to do it with their own phone.

Only 23 % of patients said they prefer in-person visits, indicating they were interested in the telemedicine service. Similar to this the patients have reported in the previous studies [30]; nearly one-quarter of families would like all future care to be in-person in this study.

We avoided in-person telemedicine service visits in 34 patients (30%). The median telemedicine visit was 2 (IQR:1-4).

Outcome

Out of these patients, at 6 months, could not follow up 3 patients.14 were not continuing treatment in AIIMS. Out of these 14 patients,4 attendants did not disclose the reason, 2 stopped treatment for personal reasons, 6 attendants believed that the patient was disease free, and 2 attendants replied that they discontinued treatment as they had difficulties with the telemedicine service.

While the assessment of disease outcome was limited by the study design, we looked at the outcomes of patients in terms of disease worsening or improving and whether it was related to the telephonic visit.

In terms of outcome, 88 with a score of 1, 20 with a score of 2, and 1 patient with a disease outcome score of 3. Score 1 represented, resolved, or disease under control. Other higher scores worsening of the disease.

There was a worsening disease condition in 21 patients(19%) with 1 death.6 Patients(5%) had a complication. Out of this, in four patients, the previous visit was telemedicine

The first was a case of SRNS, who had severe edema and SBP, even though the previous visit was a telemedicine visit, it was 3 months back, and he failed to seek medical advice at the onset of edema hence unlikely to be a complication occurring due to lack of physical visit. Another patient was Nephrotic syndrome, IFR. For this patient, though the last visit was a telemedicine consultation, this was 4 months back, here the patient presented in relapse with AKI. In this case, also they didn't turn up on time to get any consultation. The third patient was a case of steroid-resistant nephrotic

syndrome on CNI, who developed tacrolimus toxicity; even though the last was a telemedicine visit, the patient didn't comply with the advice of reporting back with tacrolimus levels on time as advised. Another was CKD stage 5 with stage 2 hypertension; the previous visit was telemedicine. The patient was asymptomatic and was found to have Hypertensive urgency during an OPD visit. The patient reported good compliance, which could have been due to a lack of formal BP recording in the clinic and faulty records being measured at home. By analysing these adverse outcomes, it was clear that teleconsultation was not the reason for adverse events. Telemedicine services effectively deliver health care and manage patients.

The outcome, at six months, was patient-reported(this was also correlated with the latest available investigations). 81 % of patients had no worsening or improved disease condition. There was a worsening in 19 %, out of which 14 % was an expected worsening of disease, and the rest 5 % had unexpected worsening or complication. Studies are done to analyse the effectiveness of telemedicine as a mode of treatment. Various studies found that telemedicine is an effective tool in many chronic diseases[6]. The role of telemedicine in pediatric Nephrology has been investigated. [12,21-25]. (as described in table 4)

In the present study, the initial disease condition was assessed, and after 6 months of enrolling, their disease condition was assessed; during this period, their need for any hospital admission for an emergency need or elective was also evaluated.

In their study on CKD patients, Judy Tana assessed the outcomes in terms of progression to ESRD, Doubling of creatinine, and Death. They compared 2 cohorts(one of the telenephrology group and another in-person visit). There was no difference in outcome in both groups [7](as described in table 2, sl no 3). Due to the COVID-19 pandemic, we could not have a comparison group, and our study population was also heterogenous as we included all patients seeking teleconsult in the present study. However, to overcome this partly, we assessed the outcome of all our patients according to a predetermined Score [Annexure - 13]. The score was designed as per the worsening severity of the disease. In the case of CKD patients, we also correlated the outcome with the initial KFT and the latest available KFT at the end of 6 months. In this group, there were a total of 24 children with CKD. 21 were CKD with a known cause, 19 were secondary to CAKUT, 1 operated case of meningomyelocele with

neurogenic bladder, and 1 was a case of nephrocalcinosis. Among these, one patient had worsening Kidney Function. Out of the unknown cause, one discontinued treatment due to personal reasons, and there was a worsening of renal function in one patient. So, in summary, out of the total 24, only 2 had worsening CKD stage(8.3%). One of the CKD patients had hypertensive urgency due to skipping drugs during the OPD visit, which required admission. But none of the patients had an acute life-threatening event.

In a study done on Pediatric Nephrology patients in Russia.[21](table 4, sl no 1). They provided online information to patients after analysing their symptoms and investigations available. They provided diagnoses and also recommendations, and information to the patients. There was overdiagnosis in 45 % of cases, 15 % were underdiagnosed, and 40 % were appropriately diagnosed. The percentage of overdiagnosis was more; the majority responded that consultation was useful(mean 4.6 on a 5-point scale).In our study, we have not made any diagnosis on just a telemedicine basis as the rules were not allowing for the same.

Other studies also support telemedicine's efficiency. In the study by Meaghan Lunney, ESRD patients reported; no differences in laboratory parameters / reduced or similar hospitalisation rates with telehealth.[15]

The study by Mittal et al on pediatric nephrology patients has reported telemedicine's effectiveness in triaging patients and avoiding unnecessary hospital visits.[22]

A study by Rupesh Raina in pediatric nephrology patients has also reported that patients reported equivalent quality and easier than in-person visits.[24]

Yue Ma did a systematic review and meta-analysis in which 15 articles were reviewed. The diseases addressed were diabetes mellitus, rheumatoid arthritis, and hypertension. The outcome in diabetes patients was assessed in terms of HbA1c; patients were followed up for 12 months, and there was an improvement in the values. In patients with Hypertension, the outcome was analysed after 6 months with respect to blood pressure control. In rheumatology, their self-management was considered a measure of outcome [6]. (as described in table 2, sl no 6). While a physical assessment of the outcome was not feasible in the background of the COVID-19 outbreak, it was clear that telemedicine did not adversely affect the clinical outcome of patients.

Satisfaction.

A systematic review of patient satisfaction with telehealth concluded that it was convenient, easy to use, enhanced communication, and, in some cases, improved outcomes [27]. (table no 5, sl no. 5)

A study by Pradeep G Paul et al. in teleophthalmology has reported 44.4% reportedteleophthalmology screening was satisfactory[26](as described in table 5, sl no 1).In our study, 92 % were satisfied, indicating better satisfaction.

The overall satisfaction of our patients was high. We used the Telemedicine usability questionnaire. From our observations, the patients receiving telemedicine services for renal-related illnesses at our centre were satisfied with the services, and the usability was good.

Satisfaction was assessed by the last 4 individual components of the TUQ questionnaire (Annexure- 7,8). The majority were satisfied, with the system, with 92 % giving a positive response.

The questionnaires assess various subscales: Usefulness, Ease of use and Learnability, interface quality, interaction quality, reliability, satisfaction, and future use.

Out of the subscales, the best scored was Usefulness, in which all the patients scored more than 4. The median score was 6(IQR(5-6)).

This was followed by Ease of use and learnability and interaction quality. For both, 99 % have given a score of more than 4. The median score was 6 for both(IQR(5-6).

98 % Responded with a score of more than 4 for the subscale interface quality, with a median score of 6(IQR:5.75-6)

Least scored subscale was Reliability; only 57% gave a positive response. The median score was 4.

92 % responded with a score of more than 4 for the subscale satisfaction and future use. The median TUQ score was 6 (IQR:5.75-6).

Out of the subscales, reliability scored the least, with a median score of 4(IQR:4-4), with only 57 % of patients giving a score of more than 4. median score of 4(IQR:4-4).

In the subscale; 'usefulness', the individual component, "Telehealth saves me time travelling to a Hospital or specialist clinic", scored more than four in all the patients.

Regarding individual components of the least scored subscale reliability- one of the components - " The system gave error messages that told me how to fix problems.", scored no positive response. The individual component-"Whenever I made a mistake using the system, I could recover easily and quickly" also was given a positive score only by 2 patients. The system failed because patients were not notified of any errors. Also, there was a poor response to the component that, "whenever a mistake happened, it was easy and quick to recover". Some patients have given a detailed explanation: they had to change their Hospital ID, increase visits to the E Mitra centre, and sometimes miss appointments and need further waiting. Another reliability component was that they felt telehealth visits were the same as in-person visits. This is probably because the conventional health consultations were in person. There is significant scope for improvement in this subscale. It relies on better training of health staff, enhancing their communication skills, improving the promptness of their responses, and adding video visits. Another individual component, which scored less than other items, was that they could see the clinician as if they met in person. Video telehealth systems could tackle this issue. However, there may be a concern related to privacy with the use of video consults for some patients as well as health personnel.

Clear laws and guidelines regarding the use of video consults are needed to address this need. Error messages could be provided; also, once a mistake happens from the patient side or due to any technical issues, there is a need to implement patient-friendly services.

In a study done on pediatric rheumatology patients, where they used TUQ to assess satisfaction. The median TUQ score in this study was 4(IQR:4-5)(Likert scale from 1-5). Within subscales, the usefulness component scored the least, with a median score of 4 [33].

(studies which used TUQ are described in table table7)

In this study, the median TUQ score was 6(IQR:5-6)(Likert scale from 1-7).

Within subscales, the reliability component scored the least with a Median score of 4(IQR:4-4). Compared to this study, the median score was positive in both the study.

Their least scored subscale was our best scored. But their least scored component had a median score of 4, which was positive according to their Likert scale. The least-scored subscale in our study reliability had a median score of 4, which was neutral(not a positive response).

In the study conducted by Layfield E et al., TUQ was used to assess satisfaction in patients visiting an ENT on a scale from 1 to 7, with 7 denoting the highest level of patient agreement. The overall average score for all questions was 6.01. Telehealth satisfaction questions received the highest marks (6.29), and Reliability questions received the lowest (4.86) [31].

In this study, on a scale from 1 to 7, with 7 denoting the highest level of patient agreement, the overall average score for all questions was 5.56. Telehealth usefulness questions received the highest marks (5.85). Reliability questions received the lowest values (4.6). The reliability score in our study was slightly less but is the least similar to their study.

In the study done in Pediatric diabetic patients (30), TUQ was used, whereas the Likert scale was used from 1-4. The Subscale 'Ease of Usability and learnability' and 'interaction quality' scored a median of 4 (IQR 3-4). The least scored was reliability, with a median of 2(IQR:1-3). The highest Likert response in this study was 4. [30].

In our study were Likert response was from 1-7, and the lowest scored was reliability, with a median of 4.

In the study, which assessed satisfaction in teledermatology, where they expressed as a percentage, the lowest score was for interaction and interface quality-85.9 %. Reliability also scored less in this study -86.7 % [34].

Though we have scope to improve, we need to assess the financial and time feasibility of providing such ideal services. Most studies report that the **reliability component** of TUQ scores the least while most patients are satisfied with their teleconsults across specialties.

Adherence

Our study assessed adherence using a questionnaire validated for CKD patients. Overall adherence was high compared to other studies which assess patient adherence [36,37]. Compared to the study which used the same questionnaire, by Ramay et al.[in 2017 to determine adherence in CKD patients, the mean adherence was 78% (a maximum of 96% and a minimum of 55%).In the present study, the mean adherence was 95% (a maximum of 100% and a minimum of 72%).

This high adherence might be because it was measured within one month after the telemedicine. Secondly, it was patient-reported, and there is a high chance of social desirability bias. We expected to find a correlation between the total TUQ score and the total Adherence score, but it did not exist. This could be because both the data are highly skewed.

There is a need for more robust methods, which also take objective measures, to assess adherence.

Another study of Tuberculosis patients compared adherence to treatment with DOT and video DOT. Compliance was better with Telemedicine. Treatment adherence was evaluated by the proportion of verified prescribed doses over 7 days per week. Pre-COVID and COVID periods' median verified adherence was generally similar (65% vs 68%, p=0.96). The overall rate of adherence was considerably greater with video DOT (median 86% [IQR 70-98%]) than with DOT (median 59% [IQR 55-64%], p0.01); this increased adherence with video DOT was noticeable in both the pre-COVID (median 98% vs 58%, p<0.01) and post-COVID period (median 80% vs 62%, p=0.01) [37]. (as described in the table 9, sl no.3)

Compared to our study, the overall adherence in the pre and post covid era was less. The median adherence in video DOT in the pre-COVID period was 98 %, nearly similar to our study, with a median of 96.6 %.

Cost analysis

We intended to study the cost incurred or saved by our patient. The cost saving varied for each patient according to the distance and age of the patient, the requirement for stay, the number of accompanying attendants, and their mode of transport. There is also a wage loss for the attendant in the case of working attendants. On analysis, it was clear that the expenditure to avail of telemedicine service was negligible compared to in-person visits. This difference was more significant in those far away, where there was a need to stay, several attendants accompanied, whether the attendants were working.

Expenditure for transport and food of the attendant was the maximum for an in-person visit.

INR **4200** was the average saving **over the six months** per patient. Median of INR 2130(820-4390). These savings were evaluated as a percentage of their family income. There was a mean savings of 5% of their family income with Telemedicine.

Considering various expenditures, the maximum cost was incurred on Transport and food. In the pediatric population, this cost will be less compared to adult patients, as there is no need for transportation for many patients. In small children, food was not separately bought, and they ate from their parents' bowls. Also, some patients have their food from relatives' houses, and some prepare and bring it from Home.

The requirement of stay was less in our patients, but some patients need an entire day for travelling, where they have to sleep during the travel, affecting their quality of life.40% didn't have any expenditure on patients' food, and only 29% had an expenditure for patients' transportation. The 15 %(n=17) of Patients required stay, out of which, 10 Patients spent on rent. 7 stayed at relatives' houses.

We have calculated the total savings for our patients in six months, INR 4,57,900. The total saving in six months was slightly higher than the visits multiplied by the mean expenditure per visit with the number of telemedicine visits as the number of visits for patients with different costs was different.

The loss as lost wages was expected to be high, but there are many patients for whom the attendants are doing jobs where official leaves are available, with no loss of pay. There was a loss of work for 75 attendants. There was a loss of wages for the attendants of 47 attendants (42 %). The rest had paid leaves. The median loss of wages was INR 300(IQR:0-500). The average loss as lost wages was INR 330

The expenditure for availing telemedicine visits was too less. The expense was for obtaining an appointment. Some Attendants were capable of getting appointments by themselves from an online portal. At the same time, others depended on E Mitra. Patients for whom a review is advised from AIIMS within the next 3 months were

given an appointment from AIIMS. The median Expenditure for. None of the attendance had any loss of wages or any expense for transportation. The only expense was for E Mitra services and appointments. Telemedicine services over 6 month period were INR 30(IQR:0-50). Another expected expenditure was for internet services, only 4 patients had to spend extra other than their routine use, for internet services.

In a study done in Australia, their total savings in one-year dollars were 31,837, almost INR 26,40,400 [12]. In this study, we have calculated the total savings for our patients in six months, INR 4,57,900, which is comparable to the study from Australia. The overall cost difference could be attributed to differences in the cost of living in both countries. (studies on cost analysis are described in table 10)

In another study done on 208 geriatric patients, there was a benefit of AUD\$ 131(INR-7261) per consultation compared to an in-person visit. In our study, this was Rs 1577. (this was calculated by taking the average cost of single consultation of all the patients) [39]. During the COVID-19 outbreak, we were not able to compare with any cohort. Both studies have proven economic benefits to the patient with Telemedicine. The difference could be explained by the difference in living standards between the two countries.

Studies in diabetic patients in Queensland have also reported the economic benefit of telemedicine. They reported savings in travel costs of \$ 517 (INR-42876) in a single consultation [40].

All of these available studies show economic benefits to the patient with Telemedicine. There is a difference in the cost-benefit. This depends on the living conditions of the country. Many of our patients were using public transport(75%). Only 25 % were using a private vehicle or Taxi. Other factors which determined were the loss of wages. Only 42 % of our attendants lost wages, and the average loss was less (INR 330), as they were daily wage workers with less pay. Despite all these, there was a benefit of 5% of the family income per patient.

None of the patients had any other expenditure other than those mentioned above.

There was a significant benefit with telemedicine services in the assessment of the overall benefit to the patients.

CONCLUSIONS

We enrolled 112 patients. The majority [23 %(n=26)] were in the age group of 1 month to 3 years .66 % were males and 34 % were females. In the majority (69%), consultation was attended by the father, while in others, attended by the mother, uncle or grandparents, and siblings. The literacy status of the ones attending telemedicine was good, only 5% were illiterate;42 % were graduates. The majority of the patients were from Jodhpur District- 35.7 %(n=40), 17 %(n=19) from Pali, 16% (n=18) from Barmer, and 10 % (n=12) from Nagaur, which are the neighbouring districts. The median distance from residence to AIIMS Jodhpur was 122.5 Km(IQR:30-250). 6% of attendants had a good understanding, 59% had an idea about the system, and the rest were unaware.

This study helped in understanding the variety of diseases, which could be managed with telemedicine. The majority of cases were of Nephrotic Syndrome-55%. Followed by CKD at 21 %, CAKUT-18%, glomerulonephritis -at 10%, UTI without CAKUT-6%, RTA at 3%, CKD with an unknown cause at 3%, and other miscellaneous conditions -at 5%.

We had a basic understanding of the disease course over the 6 months when telemedicine was also used in management. In terms of outcome, 88 had no worsening of disease (score -1), only 20 had some worsening(score -2), and 1 patient with a score of 3 indicating severe worsening(this was a case of SRNS on tacrolimus , who had a complicated relapse , with Acute kidney injury). (Score 1 represented, resolved or disease under control, and higher scores according to the severity, represented by the predetermined scoring (annexure-13).

Disease outcome was also classified into three as, static or improved, expected worsening, and unexpected worsening or complication. Here, 3 patients, who we were not able to contact were not considered

There was a worsening of the disease in 19 % of our patients, and in 14 % the worsening was expected in the natural course of the disease, for example, relapse in nephrotic syndrome. 5%(6 patients) had an unexpected worsening or complication. In 4 out of these 6 patients, the previous consultation was through telemedicine. But these were not related to telephonic consultations. Poor compliance for timely follow-up in

these patients was evident. Acute diseases, like UTI [total 7 patients, score 1-7] without other abnormalities, and diseases, which are already known to have good prognoses like SSNS[total 28 patients, score 1-25, score 2-3], had good outcomes at 6 months. On the whole telemedicine is a good modality especially in chronic diseases, for follow-up.

This study, provided the patient perspectives, on telemedicine. How it affected patient satisfaction. 92 % responded with a score of more than 4 for the subscale satisfaction and future use, the median score was 6 (IQR:5.75-6). Out of the subscales, reliability scored the least, with a median score of 4(IQR:4-4), with only 57 % of patients giving a score of more than 4. median score of 4(IQR:4-4).

The subscale, 'Usefulness', was given a score of more than 4; a 100 % positive response. The best-scored individual component was, it is Time saving for the patient. Our patients also reported a high level of satisfaction similar to other studies. We couldn't find any correlation between the basic demographic characteristics and the level of satisfaction and usability of the system. We also understood specific areas where to concentrate to have better patient satisfaction. Reliability was the component that scored least similar to the majority of others studies.

On assessing adherence, we found a high level of adherence, though it was patientreported. The median adherence score was 86(IQR-83-88) out of a total score of 89. The mean adherence was 95% (a maximum of 100% and a minimum of 72%). Among individual components, **knowledge about medication** scored the least, with a mean score of 3.85.Treatment at a distance without seeing the patient didn't affect adherence. This was assessed by the questionnaire method. There is a need for further studies if possible a combination of objective and questionnaire, with a cohort for comparison to have robust evidence.

It was clear that telemedicine is economically beneficial for the patient. In this study, we have calculated the total savings for our patients in six months, INR 4,57,900. INR **4200** was the average saving **over the six months** per patient. Median of INR 2130(820-4390). These savings were evaluated as a percentage of their family income. There was a mean savings of 4.99% of their family income with Telemedicine **[Range:0.012%-37%].** Average cost saving of INR -**1577/patient** in a single visit. This was calculated by taking the mean of the sum of the single visits of all patients.

The cost of food and transport of the attendants was the highest expenditure. Telemedicine was very cheap for the patients, with, the median expenditure to avail telemedicine services over 6 month period being INR 30(IQR:0-50).

Further studies are required to assess the expenditure for the institute.

There is an environmental benefit, as there is a saving of travel distance of 83274 Km(743 Km per patient in the 6 months). There is less fuel consumption as there is less requirement for transportation and thus less emission of pollutants. A majority of our patients used public transport it was not possible to quantify the environmental benefits.

It is apparent that telemedicine is beneficial and does not affect the disease outcome. There was a high level of patient satisfaction with telemedicine. The patient reported adherence was also high. Apart from these, there are significant monetary benefits for the patient. There is an improvement in their quality of life, as it saves time. The service is also providing environmental benefits, as it decreases, the travel distance and thus fuel consumption, leading to less emission of pollutants. Even though there are limitations to the study, it provides a basic idea, of the management of various diseases with telemedicine, the acceptance of the service by the patients, and the monetary benefits for the patients.

Recommendations

The application of telemedicine in the follow-up of chronic patients should be reinforced.

More studies, where the outcome satisfaction, adherence, and cost analysis, compare these with a cohort of patients, who receives only in-person consultation.

Laws to be laid down for video consultations to be used widely and improve the overall outcome of telemedicine.

There is a need for objective methods to be incorporated with this subjective assessment of patient adherence(like pill count, drug level, etc.)

Strengths of the study

- First of its kind of study assessing, disease outcomes, satisfaction, and adherence, from the Southeast Asian region in children attending Pediatric nephrology consultation. Previous, studies on this subject from our region have only elaborated on the patient profile using telemedicine in pediatric nephrology and have not assessed the outcomes of patients who used Telemedicine[22,23].
- Standard validated questionnaires were used for assessing satisfaction and adherence.
- Patients with diverse diseases were included and scored for disease outcomes.
- Detailed Cost analysis including all the domains of expenditure, from a Low middle-income country, perspective, was attempted, where, the cost of living is lowered compared to the regions, from where cost analysis studies are available[12,38-41].

Limitations.

- The outcome was patient-reported.
- The outcome assessment was limited by the study design as there was no standardised scoring for assessing the varied disease outcomes.
- We could not provide video consultations, as clear laws and guidelines were unavailable.
- The results would have been more significant if there had been a cohort of similar patients, who are receiving in-person consultation (RCT design not feasible due to COVID-19)
- Also, the difficulties faced by the clinician in taking decisions should have been assessed.
- Satisfaction and adherence were measured using patient-reported questionnaires. Adherence was not objectively quantified. (eg: pill count, drug level, etc.)
- Due to the COVID-19 outbreak, we could not use objective methods.

- The limitation of this assessment was that the expenditure the institute had for providing these services was not analysed.
- Also, the time the doctor spent delivering the telehealth consultations compared to straight visits needed to be assessed.

SUMMARY

Background

There are no studies evaluating the quality of telemedicine in terms of satisfaction, adherence, and outcomes; which is a widely practiced modality

Satisfaction is an accepted indicator of the performance of a healthcare service. It reflects patients' values and expectations regarding various aspects of health service

Medication compliance is critical for all aspects of pediatrics, specifically in successful treatment, disease prevention, and health promotion.

There are very few studies assessing the cost-benefit analysis, of telemedicine in pediatric nephrology.

Research Question: Do telemedicine consultations affect the patient outcome, compliance, and satisfaction in Pediatric Nephrology at AIIMS Jodhpur?

Hypothesis: Telemedicine affects patient satisfaction, compliance, and treatment outcomes in children seeking teleconsultation for pediatric renal problems

Objectives

Primary Objective

To explore the outcome of the patients with renal disease attending the telemedicine service of the pediatrics department of AIIMS Jodhpur.

Secondary objectives

- 1. To assess the satisfaction and compliance of patients taking teleconsultation in pediatric nephrology using a validated questionnaire.
- 2. To perform a cost analysis of the telemedicine service for pediatric Nephrology patients using a predetermined questionnaire

Study Design-Prospective cohort study

Study duration – Jan 2021 to December 2022.

Study place – Outpatient Department- Pediatric Nephrology clinic. Department of Pediatrics AIIMS Jodhpur.

Sample size- All consecutive patients who took teleconsultation for Pediatric Renal Problems were enrolled after obtaining Ethical Clearance from Jan 2021 to April 2022 followed by a 6-month follow-up for each patient enrolled.

Inclusion criteria:

 Patients 29 days to 18 years of age who took telemedicine consultation for Renal related issues and are now on follow-up.

Exclusion criteria:

- 1. Patients with End-stage chronic kidney disease on dialysis.
- 2. Those seeking consult in a Pediatric Nephrology clinic but not seeking care for a renal problem.

Methodology

- Those seeking a telemedicine consultation for the renal-related disease were enrolled (excluding those on dialysis).
- Enrolment was done from, March 2021- April 2022
- Details of the patients were obtained from the Hospital Information system weekly.
- Patients were followed up one month after their first telemedicine consultation and 6 months after that.
- Patient satisfaction was assessed using a standard questionnaire- Telemedicine utility questionnaire at 1 month.[Annexure-7,8]
- Compliance of the patients to treatment was assessed using a validated questionnaire at 1 month. [Annexure-9,10]
- Six months after enrolment, patients were followed up telephonically to assess the disease-specific outcome. They were scored using the following scoring system [according to the worsening of disease severity]. (score 1- disease under control or improvement, and higher score according to worsening severity.(annexure-13)

- Following this, disease outcome was also classified as, static disease course or improvement, expected worsening, and unexpected worsening or complication The patients, who discontinued the treatment were also considered in this classification.
- The cost analysis using a questionnaire- in terms of perceived cost savings by a telemedicine consultation compared to an in-person visit during six months period from enrolment(annexure-14)

Results

We enrolled 112 patients. The majority [23 %(n=26)] were in the age group of 1 month to 3 years .66 % were males and 34 % were females. In the majority(69%), consultation was attended by the father, while in others, attended by the mother, uncle or grandparents, and siblings. The literacy status of the ones attending telemedicine was good, only 5% were illiterate;42 % were graduates. The majority of the patients were from Jodhpur District- 35.7 %(n=40), 17 %(n=19) from Pali, 16% (n=18) from Barmer, and 10 % (n=12) from Nagaur, which are the neighbouring districts. The median distance from residence to AIIMS Jodhpur was 122.5 Km(IQR:30-250). Over the 6 months, our patients have saved a travel distance of 83274 km.

6% of attendants had a good understanding, 59% had an idea about the system, and the rest were unaware.

The majority of cases were of Nephrotic Syndrome-55%. Followed by CKD at 21 %, CAKUT-18%, glomerulonephritis -at 10%, UTI without CAKUT-6%, RTA at 3%, CKD with an unknown cause at 3%, and other miscellaneous conditions -at 5%. (Which included 1 of Hypercalciuria under evaluation, one each of Familial hypercalciuria with nephrocalcinosis with CKD, Atypical Haemolytic Uremic Syndrome, Renal artery stenosis with hypertension, nocturnal enuresis, and hematuria under evaluation).

Out of 112 patients, at 6 months, were not able to contact 3 patients. In terms of outcome 88 with a score of 1, 20 with a score of 2, and 1 patient with a disease outcome score of 3. [Score 1 represented, resolved, or disease under control. Other higher scores as per worsening of the disease. (annexure-13)]

There was a worsening of disease in 19 % of our patients [14 % - expected worsening.

5%(6 patients) -unexpected worsening or complication]. In 4 out of these 6 patients, who had a complication the previous consultation was through telemedicine. But the complications were not related to telephonic consultations. Poor compliance for timely follow-up in these patients was evident.

Median TUQ score is 6(IQR:5-6).

92% gave a positive response for the subscale; satisfaction and future.

Telehealth saves me time-scored highest -100 % of the patients gave a score above 4.

Subscale-reliability scored least with a median score of 4(IQR:4-4)

The median adherence score was 86(IQR-83-88) out of a total score of 89. Among individual components, **knowledge about medication** scored the least, with a mean score of 3.85.

There was a total savings of INR 4,57,900 considering 109 patients(3 lost to follow up), during six months follow up. Average cost saving of INR -1577/patient/visit. Mean savings was 4.99 % of the family income, a median of 2.16 %(IQR:0.66-5.5 %)

The Highest expenditure/per visit was for food and transport of the attendants, The median expenditure for transport and food of attendants per visit was 450(IQR,100-1000), with an average expenditure of INR 830.

Conclusion

We had a basic understanding of the disease course over the 6 months when telemedicine was also used. Even though there were complications, on detailed analysis, these happened due to a lack of any form of follow-up from the patient side. Patients who received our telemedicine service were satisfied with the treatment but did not find the system, reliable Compliance assessed with the help of a standard questionnaire was high, probably due to social desirability bias, and also compliance was assessed for a period of one month only. There was a significant cost benefit for the patient with telemedicine.

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Annexure -1



No. AIIMS/IEC/2021/3477

Date: 12/03/2021

ETHICAL CLEARANCE CERTIFICATE

Certificate Reference Number: AIIMS/IEC/2021/3312

Project title: "Exploring the utility of telemedicine for paediatric nephrology at AIIMS Jodhpur: A study of patient outcomes, satisfaction and compliance"

 Nature of Project:
 Research Project Submitted for Expedited Review

 Submitted as:
 M.D. Dissertation

 Student Name:
 Dr. Vishnu Dev P M

 Guide:
 Dr. Aliza Mittal

 Co-Guide:
 Dr. Kuldeep Singh, Dr. Siyaram Didel, Dr. Puneet Pareek & Dr. Sanjeev Misra

Institutional Ethics Committee after thorough consideration accorded its approval on above project.

The investigator may therefore commence the research from the date of this certificate, using the reference number indicated above.

Please note that the AIIMS IEC must be informed immediately of:

- Any material change in the conditions or undertakings mentioned in the document.
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research.

The Principal Investigator must report to the AIIMS IEC in the prescribed format, where applicable, bi-annually, and at the end of the project, in respect of ethical compliance.

AIIMS IEC retains the right to withdraw or amend this if:

- · Any unethical principle or practices are revealed or suspected
- · Relevant information has been withheld or misrepresented

AIIMS IEC shall have an access to any information or data at any time during the course or after completion of the project.

Please Note that this approval will be rectified whenever it is possible to hold a meeting in person of the Institutional Ethics Committee. It is possible that the PI may be asked to give more clarifications or the Institutional Ethics Committee may withhold the project. The Institutional Ethics Committee is adopting this procedure due to COVID-19 (Corona Virus) situation.

If the Institutional Ethics Committee does not get back to you, this means your project has been cleared by the IEC.

On behalf of Ethics Committee, I wish you success in your research.

Dr. Praveen Sharma

Member Secretary Institutional Ethics Committee AlIMS, Jodhpur

Basni Phase-2, Jodhpur, Rajasthan-342005; Website: www.aiimsjodhpur.edu.in; Phone: 0291-2740741 Extn. 3109 E-mail : ethicscommittee@aiimsjodhpur.edu.in; ethicscommitteeaiimsjdh@gmail.com

All India Institute of Medical Sciences Jodhpur, Rajasthan

Informed Consent Form

Title of Thesis: Exploring the utility of telemedicine for Pediatric Nephrology

at AIIMS Jodhpur: A study of the patient profile, outcomes, patient satisfaction, and compliance

Name of PG Student: DR. VISHNU DEV.P.M

Tel. No. 9633642668/_____

Patient/Volunteer Identification No._____

I,		F/o	or	M/o	or
Guardian/o	R/o				

give my full, free, voluntary consent to be a part of the study "Profile of patients utilizing the telemedicine service of the Paediatrics Department of AIIMS Jodhpur and to assess their satisfaction and compliance with the service", the procedure and nature of which has been explained to me in my own language to my full satisfaction. I confirm that I have had the opportunity to ask questions. I understand that my participation is voluntary and am aware of my right to opt out of the study at any time without giving any reason.

I understand that the information collected about me and any of my medical records may be looked at by responsible individual from the Department of Pediatrics, ALL INDIA INSTITUTE OF MEDICAL SCIENCES (AIIMS), or from regulatory authorities. I give permission for these individuals to have access to my records.

Date: _____

Place:

Signature/Left thumb

impression

This is to certify that the above consent has been obtained in my presence.

Date: _____

1. Witness1

Signature: _____

Name: _____

Address: _____

2.Witness 2

Signature: _____

Name:

Signature of PG Student

Address:

101

अखिल भारतीय आयुर्विज्ञान संस्थान जोधपुर, राजस्थान

सूचित सहमति प्रपत्र

थीसिस का शीर्षक: एम्स जोधपुर में बाल चिकित्सा नेफ्रोलॉजी के लिए टेलीमेडिसिन की उपयोगिता का पता लगाना: रोगी प्रोफ़ाइल, परिणाम, रोगी की संतुष्टि और अनुपालन का एक अध्ययन

पीजी छात्र का नाम: डॉ। विष्णु देव .पी.एम

दूरभाष। क्रमांक 9633642668 / _____

रोगी / स्वयंसेवक पहचान संख्या ._____

I, __

_ पिता / माता / अभिभावक

__निवासी

एम्स जोधपुर में बाल चिकित्सा नेफ्रोलॉजी के लिए टेलीमेडिसिन की उपयोगिता का पता लगाना: रोगी प्रोफ़ाइल, परिणाम, रोगी की संतुष्टि और अनुपालन के एक अध्ययन का एक हिस्सा बनाने के लिए मेरी पूर्ण, , स्वैच्छिक और नि: शुल्क सहमति को देता हूं । जिस अध्ययन की प्रक्रिया और प्रकृति को मुझे अपनी भाषा में अपनी पूर्ण संतुष्टि के लिए समझाया गया है। मैं पुष्टि करता हूं कि मुझे सवाल पूछने का अवसर मिला है। मैं समझता हूं कि मेरी भागीदारी स्वैच्छिक है और बिना किसी कारण के किसी भी समय अध्ययन से बाहर निकलने के मेरे अधिकार से अवगत हूं।

मैं समझता हूं कि मेरे और मेरे किसी भी मेडिकल रिकॉर्ड के बारे में एकत्रित जानकारी को अखिल भारतीय आयुर्विज्ञान संस्थान बाल रोग विभाग के जिम्मेदार व्यक्ति या नियामक अधिकारियों द्वारा देखा जा सकता है। मैं इन व्यक्तियों को अपने रिकॉर्ड तक पहुंचने की अनुमति देता हूं।

दिनांक :	जगह:	

\cdot \cdot \cdot \sim	
हस्ताक्षर / बाएं अंगूठे का निशान :	
אמווטוע / שוע טיוט עזו ויז-וויז	

यह प्रमाणित करने के लिए कि मेरी उपस्थिति में उपरोक्त सहमति प्राप्त हुई है।

दिनांक :	
जगह:	पीजी छात्र के हस्ताक्षर
१.गवाह	2.गवाह
हस्ताक्षर	हस्ताक्षर
नाम :	नामः
पता	पताः

Patient Information Sheet

Title: Exploring the utility of telemedicine for Pediatric Nephrology at AIIMS Jodhpur: A study of patient profile, outcomes, patient satisfaction, and <u>compliance</u>

Introduction: This statement describes the purpose, procedures, benefits, risks, and discomforts of the study

and your right to withdraw from the study at any point of time.

Purpose: This study is done to understand the profile of Paediatric Nephrology patients seeking care through telemedicine; their satisfaction and compliance with the service and to know whether the patient is having any cost benefit.

Study Procedure: Your data will be taken from the hospital HIS, then you will be contacted telephonically after one month of your consultation and asked some questions. You are supposed to give answers based on your experience. Then after six months of your consultation, you will be contacted telephonically again to know the outcome at that point of time,

Benefits: No monetary benefits will be given to you.

Confidentiality: Records of your study participation will be kept confidential and under safe custody. Any publication of data will not identify you by name. By signing the consent form you authorize the sharing of your study-related medical records with the regulatory authorities and the Institutional Ethical Committee.

Information regarding withdrawal: You have the right to withdraw yourself from the study at any time during the course of the study.

Contact for additional information: Any time during or after the study, you can obtain further information about the study from Dr.Vishnu Dev. P.M, Phone no.-9633642668, All India Institute of Medical Sciences, Jodhpur, Rajasthan.

रोगी सूचना पत्र

शीर्षक: एम्स जोधपुर में बाल चिकित्सा नेफ्रोलॉजी के लिए टेलीमेडिसिन की उपयोगिता का पता लगाना: रोगी की रूपरेखा, परिणाम, रोगी की संतुष्टि और अनुपालन का अध्ययन

परिचय: यह कथन अध्ययन के उद्देश्य, प्रक्रियाओं, लाभों, जोखिमों और असुविधाओं का वर्णन करता है और किसी भी समय अध्ययन से हटने का आपका अधिकार है।

उद्देश्य: यह अध्ययन टेलीमेडिसिन के माध्यम से देखभाल करने वाले बाल चिकित्सा नेफ्रोलॉजी रोगियों की प्रोफ़ाइल को समझने, उनकी संतुष्टि और सेवा के अनुपालन और यह जानने के लिए किया जाता है कि रोगी को कोई लाभ मिल रहा है या नहीं।

अध्ययन प्रक्रिया: आपका डेटा अस्पताल से लिया जाएगा, आपके परामर्श के एक महीने के बाद आपको टेलीफोन पर संपर्क किया जाएगा और कुछ प्रश्न पूछे जाएंगे। आप अपने अनुभव के आधार पर जवाब देने वाले हैं। आपके परामर्श के छह महीने बाद उस समय के परिणाम जानने के लिए आपसे टेलीफोन पर फिर से संपर्क किया जाएगा. इस समय आपको तेलएमेडिसीने सेवा से हुए खर्च या बचत के बारे में और आपके बच्चे के स्वास्थ के विषय में पूछा जाएगा

लाभः कोई मौद्रिक लाभ आपको नहीं दिया जाएगा।

गोपनीयता: सुरक्षित अभिरक्षा के तहत, आपके अध्ययन की भागीदारी के रिकॉर्ड को गोपनीय रखा जाएगा। डेटा का कोई भी प्रकाशन आपको नाम से नहीं पहचानेगा। सहमति पत्र पर हस्ताक्षर करके आप नियामक अधिकारियों और संस्थागत नैतिक समिति को अपने अध्ययन से संबंधित मेडिकल रिकॉर्ड को साझा करने को अधिकृत करते हैं।

वापसी के बारे में जानकारी: आपको अध्ययन के दौरान किसी भी समय अध्ययन से खुद को वापस लेने का अधिकार है।

अतिरिक्त जानकारी के लिए संपर्क करें: अध्ययन के दौरान या बाद में किसी भी समय, आप डॉ। विष्णु देव.पी.एम, फोन नंबर -9633642668, अखिल भारतीय आयुर्विज्ञान संस्थान, जोधपुर, राजस्थान से अध्ययन के बारे में अधिक जानकारी प्राप्त कर सकते हैं।

CASE RECORD FORM

Name:		Date:
Age:		Mobile no.
Sex:		
Address:		
Village:	District:	State:
Distance from h	nome to AIIMS Jodhpur:	
Diagnosis		
When were you first regi	stered at AIIMS Jodhpur:	
Have you taken telemedi	cine consultation in past?: ye	es/noIf Yes date:
Number of telemedicine	consultations in past(Before	enrollment):
Number of informal telec	consultations (Whatsapp/pho	ne calls):
Who takes the consultation	on: Child himself/ caregivers	3
Educational qualification	of the one attending telemed	dicine:
Father's education:	Mother	's education:
Nuclear family /joint Fam	nily:	
Family income:		
Number of calls to docto	r in last one month	
Any direct visits:	If yes How m	any:
Any hospital admissions:	: If yes how ma	any:
Visited any other doctor:	why:	
Do you understand the m	eaning of Telemedicine?	
What in your opinion is t	he meaning of telemedicine	consultation
How do you prefer to see	ek consultation:	
Do you use your own pho	one or depend on others for a	a phone ?

Who did the registration/takes appointment for your child?Do you have access to smartphone device for sharing images?If yes, do you know how to operate it to take teleconsultation?Do you have a bank account linked to your phone?If not, how did you make the payment required for seeking an appointment?Do you think this system is better for your child?

Telehealth Usability Questionnaire

	Statements	N/ A	1 2 3 4 5 6 7
1.	Telehealth improves my access to Health-care services.		DISAGREE DISAGREE AGREE
2.	Telehealth saves me time traveling to a Hospital or specialist clinic.		DISAGREE 🗆 🗆 🗆 🗆 🗆 🗆
3.	Telehealth provides for my healthcare need.		DISAGREE
4.	It was simple to use this system.		DISAGREE 🗆 🗆 🗆 🗆 🗆 🗆
5.	It was easy to learn to use the system.		DISAGREE 🗆 🗆 🗆 🗆 🗆 🗆
6.	I believe I could become productive quickly using this system		DISAGREE D D D D D D D D D D D D D
7.	The way I interact with this system is pleasant.		DISAGREE D D D D D D D D D D D D D D D D D D
8.	I like using the system.		DISAGREE
9.	The system is simple and easy to understand.		DISAGREE
10.	This system is able to do everything I would want it to be able to do.		DISAGREE
11.	I can easily talk to the clinician using the Tele-health system.		DISAGREE 🗆 🗆 🗆 🗆 🗆 🗆

12.	I can hear the clinician clearly using the Tele-health system.	DISAGREE D D D D D D D D D D D D D D D D D D
13.	I felt I was able to express myself effectively.	DISAGREE 🗆 🗆 🗆 🗆 🗆 🗆
14.	Using the telehealth system, I can see the clinician as well as if we met in person.	DISAGREE 🗆 🗆 🗆 🗆 🗆 🗆
15.	I think the visits provided over the telehealth system are the same as in- person visits.	DISAGREE D D D D D D D D D D D D D D D D D D
16.	Whenever I made a mistake using the system, I could recover easily and quickly.	DISAGREE D D D D D D D D D D D D D D D D D D
17.	The system gave error messages that clearly told me how to fix problems.	DISAGREE 🗆 🗆 🗆 🗆 🗆 🗆
18.	I feel comfortable communicating with the clinician using the telehealth system.	DISAGREE 🗆 🗆 🗆 🗆 🗆 🗆
19.	Telehealth is an acceptable way to receive Health-care services.	DISAGREE 🗆 🗆 🗆 🗆 🗆 🗆
20.	I would use telehealth services again.	DISAGREE D D D D D D D D D D D D D D D D D D
21.	Overall, I am satisfied with this telehealth system.	DISAGREE 🗆 🗆 🗆 🗆 🗆 🗆

TUQ- Hindi version

TELEHEALTH उपयोग योग्यता

	बयान	N/A	1 2 3 4 5 6 7
1.	Telehealth सवास्थ्य सेवाओं तक मेरी पहूँच		असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	में सुधार करता है ।		इस बात से सहमत
2.	Telehealth मेरा अस्पताल या विशेषज्ञ		असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	क्लिनिक तक पहुंचने के लिए समय बचाता		इस बात से सहमत
	है ।		
3.	Telehealth मेरी स्वास्थ्य संबंधी जरूरतों		असहमत 🗆 🗆 🗆 🗆 🗆
	को पूरा करता है ।		इस बात से सहमत
4.	इस प्रणाली का उपयोग करना सरल था।		असहमत 🗆 🗆 🗆 🗆 🗆
			इस बात से सहमत
5.	सिस्टम का उपयोग करना सीखना आसान		असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	था।		इस बात से सहमत
6.	मेरा मानना है कि मैं इस प्रणाली का उपयोग		असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	करके जल्दी से उपयोगी बन सकता हूं।		इस बात से सहमत
7.	जिस तरह से मैं इस प्रणाली के साथ बातचीत		असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	करता हूं वह सुखद है।		इस बात से सहमत
8.	मुझे सिस्टम का उपयोग करना पसंद है।		असहमत 🗆 🗆 🗆 🗆 🗆 🗆

		इस बात से सहमत
9.	प्रणाली सरल है और इसे समझना आसान	असहमत 🗆 🗆 🗆 🗆 🗆
	है ।	इस बात से सहमत
10.	यह प्रणाली वह सब कुछ करने में सक्षम है जो	असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	में चाहता हूँ	इस बात से सहमत
11.	मैं टेलिहेल्थ सिस्टम से चिकित्सक के साथ	असहमत 🗆 🗆 🗆 🗆 🗆
	आसानी से बात कर सकता हूं	इस बात से सहमत
12.	मैं टेलिहेल्थ सिस्टम से चिकित्सक के साथ	असहमत 🗆 🗆 🗆 🗆 🗆
	की गयी बात अच्छे से सुन सकता हूँ ।	इस बात से सहमत
13.	मुझे लगा कि मैं खुद को प्रभावी ढंग से व्यक्त	असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	करने में सक्षम हूं।	इस बात से सहमत
14	टेलीहेल्थ सिस्टम प्रयोग करते समय मैं	असहमत 🗆 🗆 🗆 🗆 🗆
	चिकित्सक को उसी तरह देखता हूं जैसे	इस बात से सहमत
	व्यक्तिगत मिलने पर।	
15.	मुझे लगता है कि टेलीहेल्थ सिस्टम पर प्रदान	असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	की जाने वाली सेवा, मरीज को सीधा डॉक्टर	इस बात से सहमत
	को दिखाने के समान होती हैं।	
16.	जब भी प्रणाली का उपयोग करते हुए गलती	असहमत 🗆 🗆 🗆 🗆 🗆
	की, मैं आसानी से और जल्दी से उस गलती	इस बात से सहमत
	को ठीक कर पाया ।	
17.	सिस्टम ने मुझे त्रुटि संदेश दिया जिसने स्पष्ट	असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	रूप से बताया कि समस्याओं को कैसे ठीक	इस बात से सहमत

	किया जाए ।	
18.	मैं टेलीहेल्थ सिस्टम का उपयोग करते हुए	असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	चिकित्सक के साथ सहजता से बातचीत	इस बात से सहमत
	कर सकता हूं।	
19.	Telehealth स्वास्थ्य सेवाएँ प्राप्त करने के	असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	लिए एक स्वीकार्य तरीका है ।	इस बात से सहमत
20.	मैं फिर से टेलीहेल्थ सेवाओं का उपयोग	असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	करूंगा।	इस बात से सहमत
21.	कुल मिलाकर, मैं इस टेलीहेल्थ प्रणाली से	असहमत 🗆 🗆 🗆 🗆 🗆 🗆
	संतुष्ट हूं।	इस बात से सहमत

इस प्रश्नावली में, 1 - दढ़ता से असहमत, 2 - असहमत, 3 - कुछ असहमत, 4 - न तो सहमत हैं और न ही असहमत हैं, 5 - कुछ सहमत हैं, 6 - सहमत हैं, 7 - दढ़ता से सहमत हैं कि दूरसंचार प्रणाली की उपयोगिता का निर्धारण करने के लिए, कुल गणना करें। और सभी कथनों की प्रतिक्रियाओं का औसत निर्धारित करें। कुल औसत जितना अधिक होगा, टेलीहेल्थ सिस्टम की उपयोगिता उतनी ही अधिक होगी।

ADHERENCE QUESTIONNAIRE

Question	Likert scale
	range of
	responses
If in any moment you observed the patient feeling sad, did you	Always=1,
stop giving them the medication (or did they stop taking the	Never=5
medication)?	
If in any moment the patient felt sick, did you stop giving the	Always=1,
patient their medication (or did they stop taking the medication)?	Never=5
Do you feel capable supporting the patient in taking their	Not at all=1,
medication to treat their illness (or do you feel capable taking	Very much=5
medication for your illness)?	
If in any moment you observed the patient feeling better, did you	Always=1,
stop giving the patient their medication (or did they stop taking	Never=5
the medication)?	
Has the patient stopped taking their medication at any time?	Always=1,
	Never=5
How would you rate the relationship you have with the doctor	Poor=1,
and	Excellent=5
the health care team?	
Do you give the patient the medications at the same time every	Never=1,
day (or does the patient take their medication at the same time	Always=5
every day)?	
In your opinion, how beneficial is taking these medications?	Not at all=1,
	Very much=5
Do you consider yourself adherent to the patients' medication	Never=1,
therapy (or your medication therapy)?	Always=5

In general, how happy are you (and the patient) since the patient	Unsatisfied=1,
started taking their medication ?	Satisfied= 5
How do you rate the intensity of the side effects experienced	Very intense=1,
related to these medications?	Not intense at
	all=5
When you receive good news about the progress of your disease	Never=1,
does your doctor use the news to encourage you to continue	Always=5
taking your medication?	
How much time do you spend taking medications ?	A lot=1,
	Not much=5
Do you think that the patient's health has improved since you	Not at all=1,
started giving them medication ?	Very much=5
How difficult do you perceive taking medication?	Very hard=1,
	Not hard at
	all=5
Do you think you have a sufficient amount of information	Insufficient=1,
regarding the medication the patient uses?	More than
	enough=5
How hard is it for you to maintain your treatment adherence, and	Very hard=1,
come to your appointments?	Not hard at
	all=5
Of all of the medications you take, how many do you take all the	None=0,
time?	All=2
Since the patient began medication therapy, have they ever	yes=0,
missed a complete day of taking their medications?	no=1
Do you or the patient use any sort of strategy to remember to	yes=0,
take their medications?	no=1

Adherence questionnaire- Hindi version.

Adherence questions, scores of allowed responses

Question	Likert scale
	range of
	responses
यदि किसी भी समय आपने रोगी को उदास देखा, तो क्या आपने उन्हें दवा देना	हमेशा = 1,
बंद कर दिया था (या क्या उन्होंने दवा लेना बंद कर दिया था)?	कभी नहीं = 5
यदि किसी भी समय रोगी बीमार महसूस करता है, तो क्या आपने रोगी को	हमेशा = 1,
उसकी दवा देना बंद कर दिया था (या क्या उन्होंने दवा लेना बंद कर दिया था)?	कभी नहीं = 5
क्या आप बीमारी के इलाज के लिए रोगी की दवा लेने में सहायता करने में	बिल्कुल नहीं =
सक्षम महसूस करते हैं (या क्या आप अपनी बीमारी की दवा लेने में सक्षम	1, बहुत ज्यादा = 5
महसूस करते हैं) ?	
यदि किसी भी समय आपने रोगी को बेहतर महसूस करते देखा, तो क्या आपने	हमेशा = 1,
रोगी को उनकी दवा देना बंद कर दिया था (या क्या उन्होंने दवा) लेना बंद कर	कभी नहीं = 5
दिया था)?	
क्या रोगी ने किसी भी समय अपनी दवा लेना बंद कर दिया था?	हमेशा = 1,
	कभी नहीं = 5
आपके डॉक्टर और स्वास्थ्य देखभाल टीम के साथ आपके संबंध को आप	गरीब = 1,
कितने अंक देंगे?	उत्कृष्ट = 5
क्या आप रोगी को हर दिन एक ही समय पर दवाइयाँ देते थे (या क्या रोगी हर	हमेशा = 1,
दिन एक ही समय पर अपनी दवा लेता था)?	कभी नहीं = 5
आपकी राय में इन दवाओं को लेना कितना फायदेमंद है?	बिल्कुल नहीं =
	1, बहुत ज्यादा = 5
क्या आप मानते है कि आप नियमित रूप से दवा लेते हैं ?	हमेशा = 1, कभी नहीं = 5
सामान्य तौर पर आप (और रोगी) कितने खुश हैं कि मरीज ने अपनी दवा लेनी	असंतुष्ट = 1,
शुरू कर दी है ?	संतुष्ट = 5
आप इन दवाओं से संबंधित दुष्प्रभावों का मूल्यांकन कैसे करते हैं?	बहुत तीव्र = 1, तीव्र नहीं = 5
जब आप अपनी बीमारी की प्रगति के बारे में अच्छी खबर प्राप्त करते हैं, तो	हमेशा = 1, कभी नहीं = 5
L	

आपका डॉक्टर आपको अपनी दवा लेने के लिए प्रोत्साहित करता है?	
दवाइयाँ लेने में आपको कितना समय लगता है?	बहुत कुछ = 1,
	अधिक नहीं =
	5
क्या आपको लगता है कि जब से आपने उन्हें दवा देना शुरू किया है, तब से	बिल्कुल नहीं =
रोगी के स्वास्थ्य में सुधार हुआ है ?	१, बहुत ज्यादा
रागा के स्वारच्य में सुवार हुआ है !	= 5
आपको दवा लेना कितना मुश्किल है?	बहुत कठिन =
	1, बिल्कुल
	कठिन नहीं =
	5
क्या आपको लगता है कि आपके पास रोगी द्वारा उपयोग की जाने वाली दवा के	अपर्याप्त = 1,
बारे में पर्याप्त जानकारी है?	पर्याप्त = 5 से
बार में पंथाप्त जानकारा ह?	अधिक
अपने उपचार को नियमित बनाएं रखना और अपनी appointment में आना	बहुत कठिन =
आपके लिए कितना कठिन है ?	1, बिल्कुल
	कठिन नहीं =
	5
आपके द्वारा ली जाने वाली सभी दवाओं में से हर बार	कोई नहीं = 0,
आप कितनी दवाइयाँ लेते है ?	सभी = 2
जाय प्रियाचा द्वाइया सरा ह ?	
जब से मरीज ने दवा लेनी शुरू की है ,क्या उन्होंने कभी पुरे दिन की दवा नहीं	हां = 0, नहीं =
ली ?	1
क्या आप या रोगी अपनी दवाइयाँ लेना याद रखने के लिए किसी प्रकार की	हां = 0, नहीं =
	1
तकनीकका उपयोग करते हैं?	

Permission for TUQ

Vishnu Dev <vishnudevpm94@gmail.com>

to parmanto

Fri, Nov 27, 2020, 9:46 PM

From Vishnu Dev

Junior Resident, pediatrics All India Institute of medical sciences, jodhpur Rajasthan, India Respected Sir

I am planning for a study to assess satisfaction in pediatric patients with renal problems attending the telemedicine services of our institute. I request you to kindly grant me permission to use your TELEHEALTH USABILITY

QUESTIONNAIRE (TUQ)

Also sir I need it in Hindi, do you have any Hindi version of the study; sent by someone who used your scale in Hindi if not kindly grant me permission to translate the questionnaire into Hindi

Also, can it be used in pediatric patients ? where our telemedicine calls will be attended by parents, not the patient Waiting for a reply soon

Thanking you Vishnu Dev

Nov 28, 2020, 5:44 AM

Parmanto, Bambang <parmanto@pitt.edu>

to me

Yes, you have the permission to use TUQ. You may find this website useful for you:

PITT Usability Questionnaire

Thanks,

--bambang

Bambang Parmanto, PhD

Professor and Chair

Department of Health Information Management

School of Health and Rehabilitation Sciences

University of Pittsburgh

Permission to use the Adherence questionnaire

Vishnu Dev <vishnudevpm94@gmail.com>

Sun, Nov 29, 2020, 1:31 AM

to bramay

From

Vishnu Dev

Junior Resident, pediatrics

All India Institute of medical sciences, jodhpur

Rajasthan, India

Respected Sir

I am planning for a study to assess compliance in pediatric patients with renal problems attending the telemedicine services of our institute. I request you to kindly grant me permission to use your Questionnaire for patient adherence; used in the study Factors associated with acceptable treatment adherence among children with chronic kidney disease in Guatemala Also, sir, I need it in Hindi, do you have any Hindi version of the study; sent by someone who used your scale in Hindi if not kindly grant me permission to do it.

Also, can it be used in pediatric patients where our telemedicine calls will be attended by parents, not the patient?t

Waiting for a reply soon

Thanking you

Vishnu Dev

Nov 30, 2020, 8:38 PM

BROOKE MONROE Ramay

bramay@uvg.edu.gt>

to alizamittal, me

Thank you for your interest in our study and using our questionnaire. You have our permission to use the questionnaire, it can be found as a supplemental file via the following link. We kindly ask that you cite our article when your data is published $\underline{https://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0186644.s003 \\ \underline{\&type=supplementa} \\ \underline{btype=supplementa} \\ \underline$

 \underline{ry} The file is available in English and Spanish, there is unfortunately no hindi version.

Sincerely,

--Brooke Ramay

Doctora en farmacia

Profesora asociada, departamento de Química Farmacia

Investigadora, Centro de Estudios en Salud

Universidad del Valle de Guatemala

Disease Outcome Score.

Disease	Outcome Sco	ore		
Nephrotic Syndrome	Remission 1	Progression + 1	Drug Toxicity +1	Complication +1
Glomerulone phritis	Remission 1	Progression + 1	Drug Toxicity +1	Complication +1
Chronic kidney Disease	Stable 1	Progression +1	Episodes of acute decompensation +1	
Hypertension	Controlled 1	Uncontrolled +1	An episode of Hypertensive urgency +1	An episode of Hypertensive emergency +2
UTI	No further episodes 1	Recurrent UTI +1		
CAKUT	Static course 1	Complication +1	Progression to CKD +1	
RTA	Growth Adequate 1	Growth inadequate +1		
Hematuria	Resolved 1	Cause Under evaluation. (1+)	Nephritis (+1)	
Hus	Remission 1	Remission with complication (+1)	Relapse (+2)	
Hypercalciuri a	Resolved 1	Stones (+1)	Obstructive symptoms (+1)	
Nocturnal enuresis	Resolved/i mproving 1	Persisting with the same frequency (+1)		

Cost analysis

Are you using a mobile phone? Yes/No
Since when have you been using a mobile phone?
How are you using Telemedicine Consultation? Own mobile/ family member/
friend/ neighbour
Any additional costs for internet for telemedicine consultation?
Number of telemedicine consultations in last six months:
The cost spent for medication for the past six months:
Total cost spent for investigations in last six months:
Is there any in-person visit to the hospital: If yes how many:
Mode of transport: private public
If private transport /Taxi, cost spent for these services:
Stay required or not during the direct visit? yes \Box No \Box
If yes, stay at a relative's house \Box stay for rent \Box
If for rent ; cost for stay:
Average cost spent for transport of the patient in a single visit:
Average cost spent for food of patient in a single visit:
Number of attendants accompanied in a single visit:
Average cost spent for transport, food, and stay of one attendant in a single visit:
Average number of days of work lost for one attendant in a single visit:
Average loss of wages of one attendant during a single visit:
Any hospital admissions: If yes how many:
Total cost spent for any procedures during hospital admissions in the last six months:

Total cost spent for bed charges during hospital admissions in the last six months

Mode of transport: private \Box	public	

Stay required or not:

If yes, Attendants stay at a relative's house \Box stay for rent \Box hospital \Box

Number of attendants accompanied in a single admission:

Average cost spent for transport, food, and stay of one attendant in a single admission:

Average number of days of work lost for one attendant in a single admission:

Average loss of wages of one attendant during a single admission:

The cost spent for telemedicine consultation

The cost spent for transportation, if required:

The cost spent for appointments:

Wages lost for attending telemedicine consultation; if any:

Approximate saving per telemedicine consultation.

S. No.	Date of Felemedicine visit	Age	Sex 1-Male, 2 - female, 3- Unknown	village/ Muncipality /local area	District	District	State	State 1- Rajasthan , 2 -Other states	Mobile Number	Distance from Residence to AIIMS Jodhpur(in Km)	Diagnosis at 1st Telemedicine visit	Diagnosis at 1st Telemedicine visit		Number of telemedicine consulations in the past	Date	Number of informal consultation in the past	who takes consultation 1- Father,2- Mother,3- Siblings,4- Uncle/Grandparents	Educational qualification of the one attending telemedicine consulation	Fathers education(MKS)	Mothers education(MKS)
1	16-03-2021	3	1	Pokharan	Jaisalmer	8	Rajasthan	1	9694906473	300	GDD secondary to birth asphyxia with chronic constipation with reccurrent UTI came for further evaluation, currently asymptomatic On septran prophylaxis	8	16-03-2021	0	0	0	1	6	6	6
2	16-03-2021	4	1	Sangariya	Jodhpur	10	Rajasthan	1	9982689199	5	Nephrotic syndrome 1 st episode acheived remmission currently on alternate day steroids	1	05-01-2021	0	0	0	1	6	6	4
3	16-03-2021	13	2	Rotla	Jalore	9	Rajasthan	1	6378064419	150	Post streptococcal glomerulonephritis Nephritis with hypertension (resolved) with RPGN Received Methylprednisolonepulse therapy in 2020, currently on prednisolone and azathioprine came for follow up, no proteinuria	6	06-10-2020	1	January-2021	1	3	6	1	1
		15 15	1	Bhopalgat Madrena colony	Jaisalmer Jodhpur	8 10	Rajasthan Rajasthan	1	7742444459 9772761718	285 15	SDNS- on MMF -Partial remmission SDNS- on MMF -remmission	2 2	07-02-2017 12-02-2019	2 0	19-01-21, 16-02-21 0	0	1	1 4	1 4	1 6
6	16-03-2021	1	1	Udasar	Barmer	2	Rajasthan	1	9982374339	250	Steroid sensitive nephrotic syndrome -1 st relapse acheived remission ,currently on alternate day steroids	1	14-07-2020	2	9-2-21, 9-03-2021	1	1	4	4	1
	16-03-2021 18-03-2021	11 8	1	Madhuban Roy Colony-Barmer	Jodhpur Barmer	10	Rajasthan Rajasthan	1	9414218724 9602206259	2 200	SDNS -in remnission- alternate day steroids SLE with CNS involvement currently under control with disseminated tuberculosis on	2	10-06-2014 07-07-2020	0	0 16-07-202,24-09-	0	1	4	4	4
	23-03-2021	6	2	muncipality Jodhpur IIT campus	Jodhpur	10	Rajasthan	1	6376119061	30	intensive phase of ATT Hypertension under control Renal calculi with HDUN with recent UTI resolved - plan to evaluate stone after 4 weeks of UTI	8	16-03-2021	0	2022,10-12-2020 0	0	1	6	6	6
10	23-03-2021	8	2	Jakir husain road,Pali	Pali	11	Rajasthan	1	9214548440	75	Urinary tract infection -1 st episode	8	16-03-2021	0	0	0	1	6	<u>6</u>	4
11	23-03-2021	15	1	Bhimda	Barmer	2	Rajasthan	1	9549599829	150	Steroid Dependent Nephrotic Syndrome, on Levamisole currently in remission with past history of CSVT	2	12-09-2017	2	06-10-2020, 03-11- 2020	2	1	6	6	5
12	23-03-2021	13	1	Sankhlon ki Dhani	Barmer	2	Rajasthan	1	6281342235	60	Steroid Sensitive Nephrotic Syndrome - 1 st Relapse-currently on Alternate day steroids currently in remmission	1	08-12-2020	0	0	0	1	2	2	1
13	23-03-2021	2	1	Rawalgarh	Jodhpur	10	Rajasthan	1	9982830651	90	High Dose steroid dependent nephrotic Syndrome, -on full dose steroids for recent relapse , acheived remmission, plan to start Levamisole	2	17-03-2021	0	0	0	3	4	1	1
14	23-03-2021	9	2	Ladnu (Muncipality)	nagaur	12	Rajasthan	1	9928032935	250	SRNS- in remnission on inj cyclophosphamide	3	09-07-2019	1	2/02/2021	1	4	5	4	4
15	23-03-2021	16	2	Bawari, Kherapa	Jodhpur	10	Rajasthan	1	7737478746	90	SRNS-on Tacrolimus still 3 + proteinuria, waiting for response after hiking tacrolimus dose with stage 2 hypertension under control 3 SLE with grade 2 Lupus Nenhritis, currently no disease activity, on Azathionrine. 3		03-09-2019	4	12/01/2021, 19/01/2021, 26/01/2021, 02/03/2021	2	3	3	1	1
16	23-03-2021	17	2	Thob	Barmer	2	Rajasthan	1	9928041572	80	SLE with grade 2 Lupus Nephritis, currently no disease activity, on Azathioprine, prednisolone, HCQ		04-06-2019	3	05/01/2021, 26/01/2021, 23/02/2021,	0	1	4	4	4
17	23-03-2021	6	1	Nokha	Bikaner	4	Rajasthan	1	8112232343	200	Steroid Resistant Nephrotic Syndrome - Tacrolimus and MMF failure plan to start inj Cyclophosphamide		04-04-2017	9	22/09/2020, 29/09/2020, 13/10/2020, 27/10/2020, 10/11/2020, 1/12/2020, 5/01/2021,9/02/2021, 23/02/2021	2	2	6	6	6
18	23-03-2021	13	2	Pali	Pali	11	Rajasthan	1	9414288369	70	Steroid Sensitive Nephrotic Syndrome, 1 st relapse ,acheived remission currently on alternate day steroids for the recent relapse	1	06-10-2020	2	29/12/2020, 16/02/2021	0	1	5	5	6
19	30-03-2021	8	2	Rupawas	Pali	11	Rajasthan	1	9928024609	100	SRNS - Partial remmission on tacrolimus ,MMF and steroids with stage 2 Hypertension.	3	06-11-2018	1	27/10/2020	1	2	5	4	5
20	30-03-2021	17	2	Rodu	nagaur	12	Rajasthan	1	9784381541	200	SDNS- Remmission on tacrolimus.	2	08-09-2020	3	19/01/2021, 02/02/2021, 02/03/2021	1	1	5	5	1
21	30-03-2021	2	1	Chhoti Khatu	nagaur	12	Rajasthan	1	9166511554	200	SRNS with MCD on renal Biopsy on cyclosporine and steroid, to see for response after hiking dose of cyclosporine with proteinuria, 3 +/2+ with stage 2 hypertension under control on labetalol,amlodipine and envas	3	30-03-2021	2	02/02/2021, 02/03/2021	1	4	5	3	2
22	30-03-2021	11	1	Bannor	Barmer	2	Rajasthan	1	9001181439	300	PIGN with stage 2 HTN under control .	6	25-02-2021	0	0	0	4	6	4	1
23	06-04-2021	3	2	Basni village	nagaur	12	Rajasthan	1	9672835447	120	SSNS- second relapse, currently on full dose steroids	1	06-04-2021	0	0	0	1	5	5	4
24	06-04-2021	12	2	Rana - Village	Pali	11	Rajasthan	1	9462609657	80	Follow up case of C 3 Glomerulonephritis was on triple immunosuppression with Tacrolimus, MMF, and steroids , which were withdrawn due to Giardiasis, currently in remnission on tacrolimus and Steroids stage 2 Hypertension under control	6	05-02-2019	7	22/09/2020,08/12/202 0, 15/12/2020,22/12/202 0,16/02/2021,23/02/2 021,9/03/2021	2	1	3	3	2
25	13-04-2021	1	1	Bhikadoi	Jaisalmer	8	Rajasthan	1	9950478017	200	CAKUT, Left HDUN with left sided grade 2 VUR on septran prophylaxis-CKD 1	4	04-06-2019	0	0	0	1	3	3	3
26	13-04-2021	9	1	Old Loco Colony, Hanuman Mandir, Ratanada	Jodhpur	10	Rajasthan	1	9414821613	8	Follow up case of b/l PUJ obstruction , status post right sided pyeloplasty withHypertension ,stage 2 under control on drugs-CKD stage 1	4	06-12-2016	2	01/09/2020 , 15/09/2020	0	1	6	6	5
27	13-04-2021	11	1	Rohilla Kallan	Jodhpur	10	Rajasthan	1	9950479255	30	Acute nephritic syndrome with endocapillary proliferation - remmission, stopped all drugs		04-12-2018	8	04/08/2020, 25/08/2020,01/09/202 0, 29/09/2020,27/10/202 0,01/12/2020, 29/12/2020,16/02/202 1	0	4	5	1	1
28	13-04-2021	9	1	Nimaj	Pali	11	Rajasthan	1	9414610370	100	0 Nephrotic Syndrome 1 st Episode acheived remission , currently on full dose steroids 1		09-03-2021	0	0	0	1	4	4	5
29	20-04-2021	16	1	131/2na, Karpura Ahmad Ali Baba Ki Dargha Ke Picche	nagaur	12	Rajasthan	1	9694148087	200	0 SRNS on sustained remmission on Tacrolimus 3		08-09-2020	2	06/10/2020, 13/10/2020	0	1	1	1	1
30	20-04-2021	16	1	Mira nagar	Jodhpur	10	Rajasthan	1	9252172651	3			06-08-2013	0	0	0	1	4	4	1
31	20-04-2021	4	2	Sarnu	Barmer	2	Rajasthan	1	7426972358	190	Steroid dependent nephrotic syndrome in remmission on alternate day steroid, but on high dose- Plan to start Steroid sparing agent	2	13-04-2021	2	two in september 2020	2	1	3	3	3
32	20-04-2021	9	1	Hathi Ram ka Oda , Jodhpur	Jodhpur	10	Rajasthan	1	9828354641	10	SPNS in release surrently on tearslinus and full does starside with stars 2		06-05-2014	0	0	2	1	2	2	1
33	20-04-2021	3	2	Akashvani Colony	Udaipur	14	Rajasthan	1	9983120073	250	SPNS Bastial commission on geolognoring and MME with store 2 Humatansian under		04-01-2021	0	0	0	1	7	7	6

Image Image <t< th=""><th></th><th></th><th></th><th></th><th>[_</th><th></th><th></th><th></th><th></th><th></th><th>SRNS in partial remmission on Cyclosporine and steroids with stage 2 Hypertension</th><th></th><th></th><th>-</th><th>Not remembering,</th><th>_</th><th></th><th></th><th></th><th>. 1</th></t<>					[_						SRNS in partial remmission on Cyclosporine and steroids with stage 2 Hypertension			-	Not remembering,	_				. 1
N N			2	Gopalpuriya	Churu	6	Rajasthan	1	6375418027	300	under control on drugs.	3	07-04-2020	3	missed previous id	2	2	4	4	4
No. No. <td>35 27</td> <td>-04-2021 4</td> <td>1</td> <td>Pannapura</td> <td>nagaur</td> <td>12</td> <td>Rajasthan</td> <td>1</td> <td>9982272593</td> <td>250</td> <td>CKD(O/C/O puv) stage 4 -CAKUT</td> <td>4</td> <td>02-04-2021</td> <td>0</td> <td>0</td> <td>0</td> <td>1</td> <td>4</td> <td>4</td> <td>4</td>	35 27	-04-2021 4	1	Pannapura	nagaur	12	Rajasthan	1	9982272593	250	CKD(O/C/O puv) stage 4 -CAKUT	4	02-04-2021	0	0	0	1	4	4	4
N N	36 04	-05-2021 3	1	Tiwari village	Jodhpur	10	Rajasthan	1	9887870839	40	Polyuria with Hypercalciuria under evaluation	9	19-09-2019	0	0	0	2	6	5	6
k k	37 11	-05-2021 5	1	Jaipur city	Jaipur	7	Rajasthan	1	7073454924	350	SDNS-remmission on levamisole, with stage 2 HTN under control on drugs	2	19-09-2020	5	17/11/2020, 15/12/2020, 05/01/2021,	0	1	6	<u>6</u>	<u>6</u>
1 1 Note N	38 11	-05-2021 15	1	Shiv -village	Barmer	2	Rajasthan	1	9587988434	250	SDNS - in remmission on levamisole and alternate day steroids	2	25-08-2020	1	01-09-2022	1	1	2	2	1
M M	39 11	-05-2021 5	2	Moosli	Barmer	2	Rajasthan	1	6350115539	300	CKD stage 5 with stage 2 Hypertension under control.	5	11-01-2021	0	0	0	4	4	2	1
n = 0 $n = 0$ <	40 25	-05-2021 15	1	Behind Lal Bunglaw	Jodhpur	10	Rajasthan	1	7568276960	12		1	27-03-2020	1	02/02/2021	0	1	2	2	1
N N	41 01	-06-2021 8	1	Ramsar Village	nagaur	12	Rajasthan	1	9950844421	200	SSNS-relapse on full dose steroids	1	01-07-2019	1	22/9/2022	0	1	4	4	1
Image Image <th< td=""><td>42 08</td><td>-06-2021 7</td><td>2</td><td>Undoo Village</td><td>Barmer</td><td>2</td><td>Rajasthan</td><td>1</td><td>9549746434</td><td>160</td><td>FRNS in remmission on levamisole</td><td>2</td><td>12-04-2019</td><td>5</td><td>31/07/2020, 04/12/2020, 18/12/2020,</td><td>0</td><td>4</td><td>5</td><td>2</td><td>1</td></th<>	42 08	-06-2021 7	2	Undoo Village	Barmer	2	Rajasthan	1	9549746434	160	FRNS in remmission on levamisole	2	12-04-2019	5	31/07/2020, 04/12/2020, 18/12/2020,	0	4	5	2	1
I I	43 08	-06-2021 7	1	Jawariya	Pali	11	Rajasthan	1	9079776908	70	Nephrotic syndrome 1 st episode acheived remmission currently on full dose steroids.	1	05-05-2021	0		0	1	2	2	1
b b c 1 Date fact 1 Date fact Date	44 15	-06-2021 17	1	Mandore	Jodhpur	10	Rajasthan	1	9983425345	20	SSNS- in relapse currently on full dose steroids	1	15-06-2021	0	0	0	4	4	2	1
N N	45 15	-06-2021 4	1	Dhool Khera	Bhilwara	3	Rajasthan	1	9509504646	250	FRNS in remmission on levamisole	2	03-09-2019	0	0	1	2	6	7	6
I I O	46 15	-06-2021 2	1	Dugastau	nagaur	12	Rajasthan	1	9166364139	200		4	03-09-2019	1	27-10-2020	2	2	3	1	3
1 1 1 0 1 0			1	-	-	2	-	1			Steroid sensitive nephrotic Syndrome, 2nd relapse , currently on alternate day therapy -	1		0		2	1	6	6	4
1 1			1	-		16	-	2				2		1		0	-		2	
N No. N			1	-	-		-	1			-	-		1		0 2		-	_	
1 1	49 15	-00-2021 17	1	Kucnaman	nagaur	12	Kajasthan	1	9414455702	250		D	29-07-2020	U		2	4	4	1	1
1 1			1					1				1		-	2020, 27-10-2020, 17- 11-2020	0	1			-
10 10 Name u 1 Banda 1 Parto 0 Control work with an expective state st			2	-	-			•								0	-	-	Ŭ	
N N			1					1							29/12/2021,	0				
9 9.0 1.0 Part			1			9		1			PIGN with RPGN completed one dose of injection cyclophosphamide with stage 2	6		0		0	4	6	4	3
10 Solution 10 Log 10 Barling 11 Solution 10 <	55 29	-06-2021 9	1	Pali	Pali	11	Rajasthan	1	7568018575	80		3	15-03-2019	2		0	1	3	3	2
5 600 7 9			1			10		1			Familial Hypercalciuria with nephrocalcinosis with CKD stage 4	5		0	0	0	2	7	5	7
b b 1 0 mb Wig Nom Vig			1			10		1				6			v	2	1	1	1	1
n n <td></td> <td></td> <td>2</td> <td></td> <td>-</td> <td>10</td> <td></td> <td>1</td> <td></td> <td></td> <td></td> <td>6</td> <td></td> <td>-</td> <td></td> <td>2</td> <td>-</td> <td></td> <td></td> <td></td>			2		-	10		1				6		-		2	-			
0 0	59 06	-07-2021 5	1	Detani- Village	Barmer	2	Rajasthan	1	9610752005	300	CAKUT-right HDUN with PUJ obstruction on septran prophylaxis CKD stage 1	4	25-06-2021	0		0	1	6	6	1
1 1 1 1 1 1 1 1 1 0 1 0	60 06	-07-2022 3	1	Shegarh -Village	Jodhpur	10	Rajasthan	1	9982245740	115		2	17-03-2021	3	13/04/2021,	0	1	1	1	1
15.0 15.0 17.0 <t< td=""><td>61 13</td><td>-07-2022 5</td><td>1</td><td>Madhav nagar birla Colony</td><td>Chittaurgarh</td><td>n 5</td><td>Rajasthan</td><td>1</td><td>88903839730</td><td>500</td><td></td><td>4</td><td>02-06-2017</td><td>0</td><td>0</td><td>0</td><td>1</td><td>7</td><td>7</td><td>6</td></t<>	61 13	-07-2022 5	1	Madhav nagar birla Colony	Chittaurgarh	n 5	Rajasthan	1	88903839730	500		4	02-06-2017	0	0	0	1	7	7	6
6 10 11 Blan Amaqual John 10 964 300 SDN in relayed control full does strondly and in the stored full does strongly and in the strongly and in the stored full does strongly and in the stored full does strongly and in the strongly an			1	÷		2	-	1				•		-	-	0	1	-	-	-
k k <td></td> <td></td> <td>1</td> <td></td> <td></td> <td>12</td> <td></td> <td>1</td> <td></td> <td></td> <td></td> <td>,</td> <td></td> <td></td> <td></td> <td>0</td> <td></td> <td></td> <td></td> <td></td>			1			12		1				,				0				
No 2 Company housing one Jointy 10 Raises A SSNS - infermission currently on alternate day shown for a freed reappe. 1 240-0.01 0 0 0 1 0 <			2					1	9351616994,			2				0	1		3	
67 2007.201 10 22 $1abbe r - bbe r$			-					1	8502889885			1		-		0	1		5	-
69 $207-201$ 8 2 Redan-Village Barner 2 Rajsthan 1 982844019 250 Chronic Kidney Disease Stage 5 with stage 2 hypertension under control on drugs 5 $13-04-2021$ 0 0 0 3 6 1 1 70 $2307-2021$ 10 10 $ada hopurs-Village$ $1as alter 8 Rajsthan 1 6377433805 250 5DNS - Last relapse in march, currently on levanisole and tapering dose of steroids. 2 12-02-2021 1 1202/2021 0 3 5 4 1 71 27-07-2021 7 2 Balora city Barner 2 Rajsthan 1 9602497698 120 SSNS- currently on iteramission, currently on alternate day steroids. 2 12-02-2021 1 11002/2021 0 1 16 6 1 72 27-07-2021 4 1 9602497698 120 SSNS- currently on iteramission, currently on alternate with rigit ureterostomy with lift$				-				1				9			1	0	1			1
$ \begin{array}{ c c c c c c c c c c c c c c c c c c c$	68 20	-07-2021 7	1	Beawar - city	Ajmer	1	Rajasthan	1	8740923387	150	SSNS - remmision for follow up	1	04-06-2019	0	0	0	1	1	1	1
73 $2307-2021$ 10 11 12002021 12022021 11 12022021 0 5 5 4 1 71 $270-2021$ 7 2 $Balora ciry$ $Barme$ 2 $Rajashan$ 1 9602497698 120 $SSNS$ -currently on treatment for clapse achieved remmission, currently on alternat 1 $11-02-2021$ 1 $11/02/2021$ 0 1 6 6 1 72 $270-72021$ 4 11 810 10 861930852 45 $CAKUT$ with CKD stage 5 Posterior urethral values with right ureterostomy with left ureterostomy with left ureterostom velocation on oneswarity management with stage 2 4 $01-08-2017$ 0 0 2 1 3 3 3 1 73 $03-08-2021$ 11 2 $Jodhpur - ciry$ $Jodhpur$ 10 $Rajashan$ 1 869692228 10 $Distal RTA$ with sensorineural hearing loss for follow up 7 $13-02-2018$ 0 0 2 4 6 5 4 7 $03-08-2021$ 3 <td>69 20</td> <td>-07-2021 8</td> <td>2</td> <td>Redana -Village</td> <td>Barmer</td> <td>2</td> <td>Rajasthan</td> <td>1</td> <td>9828844019</td> <td>250</td> <td>Chronic Kidney Disease Stage 5 with stage 2 hypertension under control on drugs</td> <td>5</td> <td>13-04-2021</td> <td>0</td> <td>0</td> <td>0</td> <td>3</td> <td>6</td> <td>1</td> <td>1</td>	69 20	-07-2021 8	2	Redana -Village	Barmer	2	Rajasthan	1	9828844019	250	Chronic Kidney Disease Stage 5 with stage 2 hypertension under control on drugs	5	13-04-2021	0	0	0	3	6	1	1
71 $270-201$ 74 2 $Baldra city$ $Bame$ 2 $Rajashan$ 1 96024768 120 $SSNS- currently on treatment for relapse achived remnission, currently on alternate d_{dy steroids.} 1 1102/2021 0 1 6 6 1 72 2707-2021 4^{4} 21 Netra Village Jodhpur 10 Rajashan 11 8619306852 45 CAKUT with CKD stage 5 Poterior uncervative management with right ureterostomy with left ureterostom construct remanagement with right ureterostomy with left ureterostomy with left ureterostom construct remanagement with right ureterostomy with left ureterostomy with left ureterostom construct remanagement with right ureterostomy with left ureterostomy with left ureterostom construct remanagement with remana$	70 23	-07-2021 10	1	Madhopura- Village	Jaisalmer	8	Rajasthan	1	6377433805	250		2	12-02-2021	1	12/02/2021	0	3	5	4	1
72 $27-07-2021$ 4 1 Netra VillageJodhpur 10 $Rajashan$ 1 8619306852 45 $CAKUT$ with CKD stage 5 Posterior urbanal values with right ureterostomy with left ureterostomy closed post PUV fulgration on conservative management with stage 2 Hypertension under control on drugs on septran prophylaxis. 0 0 2 1 3 3 1 73 $03-08-2021$ 11 2 Jodhpur - cityJodhpur 10 Rajashan 1 8696922281 10 Distal RTA with sensorineural hearing loss for follow up 7 $13-02-2018$ 0 0 2 4 6 5 4 74 $03-08-2021$ 3 2 Jodhpur - cityJodhpur 10 Rajashan 1 8696922281 10 Distal RTA with sensorineural hearing loss for follow up 7 $13-02-2018$ 0 0 2 4 6 5 4 75 $03-08-2021$ 10 2 Mathania, VillageIodebury 10 Rajashan 1 995076171 60 Follow up case of C3 Glomeentone for follow up 6 $03-03-2018$ 4 4 4 4 4 4 4 4 4 75 $03-08-2021$ 10 2 Mathania, VillageIodebury 10 Rajasthan 1 995076171 60 Follow up case of C3 Glomeentone for follow up 6 $03-03-2018$ 4 4 4 4 4 4	71 27	-07-2021 7	2	Balotra city	Barmer	2	Rajasthan	1	9602497698	120	SSNS- currently on treatment for relapse achieved remmission, currently on alternate	1	11-02-2021	1	11/02/2021	0	1	6	6	1
73 03-08-2021 11 2 Jodhpur -city Jodhpur 10 Rajasthan 1 869692281 10 Distal RTA with sensorineural hearing loss for follow up 7 13-02-2018 0 0 2 4 6 5 4 74 03-08-2021 3 2 Jodhpur - city Jodhpur - city Jodhpur 4 1 86969228 10 Distal RTA with sensorineural hearing loss for follow up 7 20-03-2019 1 16/02/2021 2 4 6 5 4 75 03-08-2021 10 2 4 6 5 6 6 5 4 75 03-08-2021 10 2 4 6 5 4 <t< td=""><td>72 27</td><td>-07-2021 4</td><td>1</td><td>Netra Village</td><td>Jodhpur</td><td>10</td><td>Rajasthan</td><td>1</td><td>8619306852</td><td>45</td><td>CAKUT with CKD stage 5 Posterior urethral valves with right ureterostomy with left ureterostomy closed post PUV fulgration on conservative management with stage 2</td><td>4</td><td>01-08-2017</td><td>0</td><td>0</td><td>2</td><td>1</td><td>3</td><td>3</td><td>1</td></t<>	72 27	-07-2021 4	1	Netra Village	Jodhpur	10	Rajasthan	1	8619306852	45	CAKUT with CKD stage 5 Posterior urethral valves with right ureterostomy with left ureterostomy closed post PUV fulgration on conservative management with stage 2	4	01-08-2017	0	0	2	1	3	3	1
75 03-08-2021 10 2 Mathemia Village Lothnur 10 Rejection for follow up case of C3 Glomentioneshrips with normal renal function for follow up case of C3 Glomentioneshrips with normal renal function for follow up											Distal RTA with sensorineural hearing loss for follow up			0				-	-	
02/03/2020								1				6		4	19/05/2020, 14/07/2020, 11/08/2020,	0	4			

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76 03-08-2021	11	1	Bhadwa- Village	nagaur	12	Rajasthan	1	7737877638	230	CKD stage 5 with CAKUT(BB/l VUR with HDUN)- for second opinion	4	03-08-2021	0	0	0	1	6	6	5
77 03-08-2021	5	1	Pali(Mothers job)	Pali	11	Rajasthan	1	9918550666	100	SDNS in remmission on levamisole	2	06-04-2018	0	0	0	2	6	5	6
78 10-08-2021	14	2	Meethri - Village	nagaur	12	Rajasthan	1	7891439798	250	Steroid sensitive nephrotic Syndrome- remission currently on alternate day steroids for a recent relapse	1	23-02-2021	2	23/02/2021, 02/03/2021	0	4	4	1	1
79 10-08-2021	13	1	Bhagali Sindlan - Village.	Jalore	9	Rajasthan	1	9001745523	170	CKD stage 1-b/l VUR - CKD stage 1 follow up , not on any drugs	4	08-05-2018	0	0	0	1	3	3	1
80 10-08-2021	7	2	Pratap nagar	Jodhpur	10	Rajasthan	1	7339786303	10	RTA with proximal tubule dysfunction with repeated fractures for follow up	7	02-02-2016	0	0	0	2	2	4	2
81 17-08-2021	9	2	Degana -village	nagaur	12	Rajasthan	1	9667754224	180	SSNS- Remmission for follow up	1	05-02-2019	0	0	0	1	5	5	1
82 24-08-2021	15	1	nandiya Kallan-Village	Jodhpur	10	Rajasthan	1	9602428610	50	SDNS- Relapse currently on full dose steroids.	2	26-07-2018	0	0	0	1	3	3	4
83 24-08-2021	4	1	Sheoganj -Town	Sirohi	13	Rajasthan	1	9782246374	175	Hematuria cause under evaluation with vitamin D deficiency	9	17-08-2021	0	0	0	1	6	6	5
84 31-08-2021	16	1	Bhandari -village	nagaur	12	Rajasthan	1	9649299834	250	SSNS -remmission currently on alternate day steroids for a recent relapse	1	31-08-2021	0	0	0	1	1	1	1
85 31-08-2021	1	1	Sarvodaya nagar-urban	Pali	11	Rajasthan	1	9828571007	80	Recurrent complicated UTI -Cause under evaluation on septran prophylaxis	8	31-08-2021	0	0	0	1	6	6	6
86 07-09-2021	17	2	Chopasni	Jodhpur	10	Rajasthan	1	9461268748	8	SDNS in remmission on alternate day steroids.	2	05-03-2019	0	0	2	1	5	5	6
87 07-09-2021	15	1	Gorchhiya Ka Bera-Village	Jodhpur	10	Rajasthan	1	9079265726	80	SDNS in remmission on alternate day steroids.	2	06-06-2017	1	22/12/2020	0	1	6	6	3
88 07-09-2021	14	1	BJS colony- Jodhpur	Jodhpur	10	Rajasthan	1	9597113358	10	SDNS-in remmission after Rituximab for follow up	2	02-04-2018	0	0	0	1	6	6	6
	14				10	-						1		08/09/2020,	-		0	0	
89 28-09-2021	6	1	Sirohi city	Sirohi	13	Rajasthan	1	9828073730	180	Steroid sensitive nephrotic syndrome - in remission for follow up	1	06-03-2018	2	15/09/2020	0	1	6	6	5
90 05-10-2021	3	1	Jodhpur	Jodhpur	10	Rajasthan	1	7665748849	12	F/c/o PUV(Post Fulguration) , with Reccurrent UTI on septran prophylaxis CKD stage 1	4	29-12-2020	1	12/01/2021	2	2	7	6	7
91 05-10-2021	13	1	Sanjoo Village	nagaur	12	Rajasthan	1	8279205551	200	Nephrotic Syndrome - First episode acheived remmission, currently on alternate day steroids	1	21-09-2021	0	0	0	1	2	2	1
92 30-11-2021	9	1	Khalijal- Village	Jodhpur	10	Rajasthan	1	9783138595	35	SDNS in remmission on alternate day steroids.	2	08-08-2017	4	27/10/2020, 03/11/2020, 17/11/2020, 16/02/2021	0	1	3	3	1
93 14-12-2021	1	2	BJS colony	Jodhpur	10	Rajasthan	1	9351396807	12	Nephrotic Syndrome 1 st Episode-acheived remission , currently on alternate day steroids.	1	16-10-2021	0	0	0	2	6	6	6
94 09-11-2021	3	1	Jodhpur- town	Jodhpur	10	Rajasthan	1	7976456414	12	Reccurrent UTI cause under evaluation on septran prophylaxis	8	02-11-2021	0	0	0	1	6	6	6
95 09-11-2021	16	2	Dhorimanna	Barmer	2	Rajasthan	1	9079630130	260	CKD stage 2 with Hypertension under control on medication	5	14-10-2021	0	0	0	1	4	4	3
96 16-11-2021	6	1	Punariya -Village	Pali	11	Rajasthan	1	9587715665	125	SSNS-IFR-in remmission currently on alternate day steroids for a recent relapse	1	08-11-2019	0	0	0	1	6	6	2
97 14-12-2021	3	1	Ratnada -Town	Jodhpur	10	Rajasthan	1	9660712131	16	Stage 2 Hypertension with renal artery stenosis with Concentric LVH with Hypertensive retinopathy	9	10-03-2020	0	0	0	2	6	6	6
98 14-12-2021	3	1	Mandore - Village	Jodhpur	10	Rajasthan	1	9784593190	30	Developmental delay with microcephaly with Nephrotic Syndrome - 1 st Episode acheived remission currently on alternate day steroids	1	05-03-2019	0	0	0	1	6	6	6
99 14-12-2021	2	1	Soyla -village	Jodhpur	10	Rajasthan	1	9001696093	80	SSNS in remission for follow up	1	07-12-2021	0	0	0	1	6	6	6
100 14-12-2021	0.5	1	Ajmer -city	Ajmer	1	Rajasthan	1	9460545722	280	CAKUT-MCKD Left stage 1 CKD	4	23-11-2021	0	0	0	1	5	5	6
101 28-12-2021	3	1	Chintupurni-village	Una	15	Himachal Pradesh	2		900	SSNS -1 st Relapse acheived remission, currently on alternate day steorids.	1	30-11-2021	0	0	0	1	6	6	6
102 28-12-2021	3	1	nagaur -city	nagaur	12	Rajasthan	1	7737666821	150	PUV(operated) with CKD stage 5 with anemia of CKD with stage 2 Hypertension under control on medication	4	06-03-2018	0	0	3	1	6	6	6
103 18-01-2022	12	1	Derasar Village	Barmer	2	Rajasthan	1	9468552229	270	CAKUT(PUV- operated)with CKD stage 5 with stage 2 Hypertension under control on medication	4	05-02-2019	0	0	0	4	5	2	2
104 25-01-2022	4	2	Chomu village	Jaipur	7	Rajasthan	1	9610778006	350	SSNS 1 st relapse, currently in relapse, on full dose steroids.	1	30-11-2021	0	0	0	1	6	6	6
105 08-02-2022	5	1	Dhool Khera Village	Bhilwara	3	Rajasthan	1	9509504646	250	SSNS -1 st relapse scheived remission , currently on alternate day steroids	1	03-03-2020	0	0	0	2	6	6	6
106 01-02-2022	13	1	Firozpura Village	nagaur	12	Rajasthan	1	9602780635	200	CAKUT -Left single kidney with stage 2 hypertension under control on drugs.	4	07-06-2022	0	0	2	4	6	1	1
107 08-02-2022	6	2	Chopasni Housing board	Jodhpur	10	Rajasthan	1	8824034526	8	O/c/o MMC ,with right kidney absent ,currently on CIC and septran prophylaxis.	4	06-10-2015	2	22/09/2020, 09/02/2021	4	2	6	6	6
108 22-02-2022	17	2	Merti Gate	Jodhpur	10	Rajasthan	1	9468554111	6	Distal RTA with Hypothyroidism for follow up	7	02-02-2016	2	19/01/2021, 02/02/2021	2	1	6	6	6
109 22-02-2022	5	1	Jalwana - village	nagaur	12	Rjasthan	1	9079112650	180	CAKUT (operated AUV)CKD stage 4 with stage 2 Hypertension under control on drugs, on septran prophylaxis.	4	31-08-2021	0	0	0	1	6	6	3
110 22-03-2022	9	2	Balotra- town	Barmer	2	Rajasthan	1	9772575505	100	Recurrent UTI, to rule out CAKUT	8	15-03-2022	0	0	0	1	4	4	4
111 05-04-2022	3	1	Rani Bazar	Bikaner	4	Rajasthan	1	9024220597	250	SDNS on alternate day steroids in remmission.	2	03-03-2022	0	0	0	1	5	5	6
112 12-04-2022	9	2	Abu road city	Sirohi	13	Rajasthan	1	7014918351	250	UTI 1st episode	8	12-04-2022	0	0	0	1	6	6	6

Nuclear/Joint family 1 -Nuclear, 2 -Joint	Family Income/Year(In Lakhs)	Number of calls to doctor in the last one month	No of direct visits in last one month	Why ?0 -not applicable, 1- Investigations, 2- Routine Follow up, 3- Both investigations and Routine follow up,4- Disease worsening,5-non nephro related disease related visit	No of Hopital admissions in last one month how many	.Type; 0- no admission,1-elective admission/Unrelated to disease,2- Emergency due to complication	No of visits to other hospital or clinic	why 0-Not applicable,1-Reason cannot be disclosed,2- Continuing previous follow up there,3-Non nephro related illnes,4- Dissatisfied with the current management	Telemedicine consultations proir to administration of TUQ(including Informal Consultation)	Do you understand the meaning of telemedicine/Have you heard of telemedicine. Option 1 - Yes, Option 2- No	What in your opinion is the meaning of telemedicine 0- No comments, 1- Consultation through phone, 2- other detailed answers.	How do you prefer to seek consultation. 1 - Telemedicine,2- Straight Visit. 3 - Neutral	Do you use use your own phone(1) or Depend on others (2)	who did registration for your child,0-Done from AIIMS, 1-Done by attendant, 2-Done by Emitra, 3- Done by other persons	for sharing images	how to operate it to take consultation.	How did you make payment required for seeking appointment, 0-Direct payment at AIIMS/No payment made, 1 - Cashless payment from own account ,2-Payment at E mitra,3 - Cashless payment from other persons account.	Do you think this system is better for you child?.0-0 1- Yes , 2 -No	1.Telehealth improves my access toHealth- care services.
2	1.8	2	1	3	0	0	0	0	2	1	1	3	1	3	1	1	3	1	7
2	1	1	0	0	0	0	0	0	1	1	1	2	1	2	1	1	2	1	5
1	0.6	1	0	0	0	0	0	0	3	1	1	1	1	1	1	1	1	1	6
2	0.5	2 2	0	0	0	0	0	0	4 2	1	1	1 3	1	0	1	1	0	1	6 6
2	2	1	0	0	0	0	0	0	4	1 2	1	1	1	0	1	1	0	1 0	6
2	7	1	0	0	0	0	0	0	4	1	2	1	1	1	1	1	1	1	4 6
1	5	1	0	0	0	0	0	0	1	1	2	2	1	1	1	1	1 2	1	5
2	1	2	0	0	0	0	0	0	6	1	1	1	1	2	1	1	2	1	6
2	0.6	2	0	0	0	0	0	0	2	1	1	1	1	3	1	1	3	1	6
2	0.6	3	0	0	0	0	0	0	3	1	1	3	1	2	1	1	2	1	5
2	0.8	1	1	3	1	1	0	0	3	1	1	2	1	1	1	1	1	1	6
2	0.6	2	1	2	0	0	0	0	8	1	1	1	1	0	1	1	0	1	6
1	1.2	1	1	3	0	0	0	0	4	1	1	1	1	2	1	1	2	1	7
2	2	3	0	0	0	0	0	0	14	1	1	1	1	1	1	1	1	1	7
1	3	2	0	0	0	0	0	0	4	1	1	3	1	0	1	1	0	1	6
2	0.8	2	0		0	-		0		2	0	1	1	0	1	1		1	6
2	1	1	0	0	0	0	0	0	5	2	0	3	1	2	1	1	2	1	6
2	0.8	2	0	0	0	0	0	0	5	1	1	3	1	1	1	1	1	1	6
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"2. Telehealth saves me time traveling to aHospital or specialist clinic."	3.Telehealth provides for my healthcare need.	 It was simple to use this system. 	 It was easy to learn to use the system. 	"6. I believe I could become productive quickly using this system"	"7. The way I interact with this system is pleasant."	8. I like using the system.	"9. The system is simple and easy tounderstand."	"10. This system is able to do everything I would want it to be able to do."		"12. I can hear the clinician clearly using theTele-health system."	13. I felt I was able to express myself effectively.		provided over the telehealth system are	"16. Whenever I made a mistake using thesystem, I could recover easily and quickly."	error messages that	"18. I feel comfortable communicating with theclinician using the telehealth system."	"19. Telehealth is an acceptable way to receiveHealth-care services."	20. I would use telehealth services again.	"21. Overall, I am satisfied with this telehealthsystem."
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7	6	7	7	6	7	7	7	7	7	7	7	6	6	4	4	7	7	7	7
7	5	6	6	5	6	6	6	5	6	6	6	4	4	4	4	6	6	6	6
7	6	7	7	6	7	7	7	6	7	7	7	6	6	4	4	6	6	6	6
6	6	6	6	6	6	6	6	6	6	6	6	6	6	4	4	6	6	6	6
7	5	6	6	5	6	6	6	5	6	6	5	4	4	4	4	6	6	6	6
7	6	7	7	5	6	6	6	6	6	6	6	5	4	4	4	6	6	6	6
7	6	7	6	7	7	7	7	6	7	7	6	6	6	4	4	7	7	7	7
6	5	6	6	5	5	6	6	5	6	6	5	5	5	4	4	5	6	6	6
7	6	7	7	7	7	7	7	6	7	7	7	6	6	4	4	7	7	7	7
7	6	6	7	6	6	6	6	6	7	7	6	5	5	2	1	6	6	6	6
7	6	7	7	6	7	7	7	6	7	7	7	5	6	3	3	7	7	7	7
7	6	6	6	5	6	6	6	6 5	6	6	5	4 5	4 4	4	4	6	6	6	6
7	5	6	6	4	6	5	6	5	6	6	5	4	3	4 4	4 4	6	5	5	5

Total TUQ score	1.If in any moment you observed the patient feeling sad, did you stop giving them the medication (or did they stop taking the medication)?	2.If in any moment the patient felt sick, did you stop giving the patient their medication (or did they stop taking the medication)?	3.Do you feel capable supporting the patient in taking their medication to treat their illness (or do you feel capable taking medication for your illness)?	4.If in any moment you observed the patient feeling better, did you stop giving the patient their medication (or did they stop taking the medication)?	5.Has the patient stopped taking their medication at any time?	"6.How would you rate the relationship you have with the doctor andthe health care team?"	7.Do you give the patient the medications at the same time every day (or does the patient take their medication at the same time every day)?	8.In your opinion, how beneficial is taking these medications?	9.Do you consider yourself adherent to the patients' medication therapy (or your medication therapy)?	10.In general, how happy are you (and the patient) since the patient started taking their medication ?	side effects	12. When you receive good news about the progress of your disease does your doctor use the news to encourage you to continue taking your medication?	13.How much time do you spend taking medications	14.Do you think that the patient's health has improved since you started giving them medication	15.How difficult do you perceive taking medication	16.Do you think you have a sufficient amount of information regarding the medication the patient uses	17.How hard is it for you to maintain your treatment adherence, and come to your appointments	18.Of all of the medications you take, how many do you take all the time?	19.Since the patient began medication therapy for ESRD, have they ever missed a complete day of taking their medications?
121	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	2	1
110	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	5	5	2	1
130	5	5	5	5	5	5	5	5	5	5	4	4	5	5	4	3	4	2	1
126 128	5	5	5	4 5	4 5	4 5	5	5	4 5	3 4	4 5	4 5	5 5	4 5	4 5	4 5	5	2 2	1
122	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	3	5	2	1
85 126	5	5	5	5	5	4 5	5	5	5	3 4	5	5	5	5	5	5	4 5	2 2	1
96	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	2	1
114	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	4	5	2	1
122	5	5	5	5	5	5	4	5	5	4	4	5	4	5	5	5	5	2	0
99	5	5	5	5	5	5	4	3	5	3	4	4	4	3	4	4	4	2	0
117	5	5	5	5	5	5	5	5	5	5	4	5	5	4	5	4	4	2	0
122	5	5	4	5	5	4	4	4	4	4	4	4	4	5	4	3	4	1	0
133	5	5	5	5	5	5	4	5	5	5	4	5	5	5	4	3	4	2	1
129	5	5	5	5	5	5	5	4	5	3	3	5	5	4	5	5	4	2	I
122	5	5	5	5	5	5	5	5	5	5	3	5	5	5	4	4	5	2	1
123	5	5	5	5	5	5	5	4	5	3	4	5	5	4	5	3	4	2	1
120	5	5	5	5	5	5	4	5	5	5	4	5	5	5	5	3	5	2	1
122	5	5	5	5	5	5	4	5	5	3	4	5	5	5	5	3	4	2	1
128	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	4	5	2	1
119	5	5	5	4	4	5	4	5	5	4	4	5	5	5	5	4	4	2	1
124	5	5	5	5	5	5	5	5	5	4	3	5	5	5	5	3	5	2	1
119	5	5	5	3	3	5	5	4	4	4	5	4	5	4	5	3	3	1	0
118	5	5	5	5	5	5	4	5	5	4	5	5	5	5	5	3	4	2	1
123	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	3	5	2	1
122	5	5	5	5	5	5	5	5	5	5	3	5	5	5	5	3	5	2	1
138		5	5	5	5	5	5	5	5	4	4	5	5	5	5	3	5	2	1
138	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	3	5	2	1
120	5	5	5	5	5	5	5	4	4	4	4	5	5	5	5	3	4	2	1
90		5	5	5	5	5	5	5	5	2	3	5	5	5	5	2	4	2	1
122	5	5	5	5	5	5	5	5	5	4	4	5	4	5	5	5	5	2	1

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121	5	5	5	5	5	5	5	4	5	4	4	5	5	5	4	4	5	2	1
120	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	3	5	2	1
87	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	3	5	2	1
123	5	5	5	5	5	5	5	5	5	5	3	5	5	5	5	5	5	2	1
119	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	3	5	2	1
120	5	5	5	5	5	5	4	5	5	4	4	5	5	5	5	3	5	2	1
120	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	3	5	2	1
127	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	5	2	1
132	5	5	5	5	5	5	5	5	5	4	4	5	5	5	5	3	5	2	1
85	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	2	5	2	1
123	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	3	5	2	1
135	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	5	2	1
124	5	5	5	5	5	5	5	4	5	4	5	5	5	4	5	3	5	2	1
112	5	5	5	5	5	5	5	5	5	4	4	5	5	5	5	5	5	2	1
99	5	5	5	5	5	5	5	4	5	4	3	5	5	4	5	4	5		1
132	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	3	5	2	1
132	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	2	1
118	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	4	5	2	1
141	5	5	5	5	5	5	5 4	5 4	5	5 4	5	5	5	5	5	5 4	5	2	1
120	3	3	5	5	3	3	4	4	5	4	4	5	3	4	5	4	3	2	1
114	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	5	2	1
120	5	5	5	5	5	5	4	4	5	4	4	5	5	4	5	3	5	2	1
137	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	2	1
120	5	5	5	5	5	5	5	5	4	4	4	5	5	5	5	3	5	2	1
116	5	5	5	5	5	5	5	5	5	5	5	5	5	4	5	3	5	2	1
90	5	5	5	5	5	5	4	4	4	4	4	5	4	5	5	3	4	2	1
83	5	5	5	5	5	5	5	5	5	3	5	5	5	5	5	5	5	2	1
94	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	5	5	2	1
121	5	5	5	5	5	5	5	5 4	5	5	5	5	5	5	5	4	5	2	1
86	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	2	1
106	5	5	5	5	5	5	5	5	5	4	4	5	5	5	5	5	5	2	1
88	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	4	5	2	1
99	5	5	5			5	4	5	5	4	4	5	5	5	5	3	5	2	0
117	5	5	5	5	5	5	4	4	5	4	5	5	5	4	5	4	5	2	1
118	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	4	5	2	1
123	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	4	5	2	1
121	5	5	5	5	5	5	5	5	5	4	5	5	5	4	5	3	5	2	1
113 113	5	5 5	5	5 5	5 5	5	5 5	5 5	5	4 4	5	5	5 5	5 5	5	5	5 5	2 2	1
120	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	4	5	2	1

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89	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	4	5	2	1
124	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	5	2	1
120	5	5	5	5	5	5	4	5	5	4	5	5	5	5	5	3	5	2	1
89	5	5	5	5	5	5	4	4	5	4	5	5	5	4	4	3	5	2	0
100 119	5	5	5	5	5	5	4 4	5	5	4 4	5 4	5	5	5	5	4	5	2 2	1
105	5	5	5	5	5	5	4	4	5	3	4	5	5	4	5	3	5	2	1
100	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	4	5	2	1
125	5	5	5	5	5	5	5 4	5	5	4 5	5	5	5	5	5	4	5	2	1
98	5	5	5	5	5	5	4	4	5	3	4	5	5	4	5	4	5	2	1
101	5	5	5	5	5	5	5	4	5	4	3	5	5	5	4	4	5	2	1
128	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	2	1
119	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	2	1
134	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	2	1
119	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	3	5	2	1
104	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	3	5	2	1
139	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	2	1
89	5	5	5	1	1	5	5	3	2	2	5	5	5	2	5	2	5	1	0
113	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	2	1
137	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	5	2	1
91	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	4	5	2	1
105	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	4	5	2	1
137	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	5	2	1
116	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	4	5	2	1
131	5	5	5	5	5	5	5	5	5	4	4	5	5	4	5	4	5	2	1
122	5	5	5	5	5	5	5	5	5	3	4	5	5	5	5	4	5	2	1
115	5	5	5	5	5	5	4	5	5	4	5	5	4	4	5	3	5	2	1
121	5	5	5	5	5	5	5	5	5	3	4	5	5	5	5	4	5	2	1
135	5	5	5	5	5	5	5	5	5	4	4	5	5	5	5	4	5	2	1
114	5	5	5	5	5	5	4	4	5	3	4	5	5	5	5	3	5	2	1
137	5	5	5	5	5	5	5	5	5	4	5	5	5	4	5	4	5	2	1
119	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5	3	5	2	1
133	5	5	5	5	5	5	5	4	5	4	5	5	5	5	5	3	5	2	1
117	5	5	5	5	5	5	4	5	5	5	5	5	5	5	5	3	5	2	1
117 108	5	5	5	5	5	5	5 4	4 5	5	4 5	4 5	5	5	5	5	3 4	5	2	1
100	5	5	, , , , , , , , , , , , , , , , , , ,				I									Ŧ	3	4	1

20.Do you or the patient use any sort of strategy to remember to take their medications?	Total score	Percentage adherence	1.Are you using mobile ? Yes /No	2.Since when ,you are using mobile phone?(In Years)	3.How are you attending telemedicine consultation: own mobile,Family members, friends, Neighbour.	4.Number of telemedicine consultation in the last 6 months?	5.Cost spent for medication in past 6 months?	6.Total cost spent for investigation in last 6 months?	7. How many straight visit in last 6 months	8.Why 20 -not applicable, 1- Investigations, 2- Routine Follow up, 3- Both investigations and Routine follow up,4- Disease worsening,5-non nephro related disease related visit	9.Was it avoidable-1- No ,2-Yes	 Mode of transport ;Public or private? (if a straight visit, was there or if he would have come/option 1 public ,2 private 		12.Stay required or not ,during in person visit? Option 1 yes ,2 no	relatives house(1) or		15.Average cost spent for food of patient in a single visit:		17.Total cost spent for the patient (food and transport-excluding transport cost of taxi and private)
1	89	100	1	4	1	2	3600	3000	1	5	1	1	0	1	2	1000	300	0	300
1	88	98.87640449	1	5	1	4	4200	900	2	1	1	2	50	2	0	0	50	0	50
1	83	93.25842697	1	4	1	1	1000	500	0	0	0	1	0	1	2	500	150	400	550
1	78 88	87.64044944 98.87640449	1	5 22	1	2 2	14600 18000	3200 1500	3	3	1	1 2	0 50	1 2	0	0	150 70	500 0	650 70
1	87	97.75280899	1	5	1	1	300	300	0	0	0	1	0	1	2	500	100	0	100
1	85 88	95.50561798	1	5	1	2 4	1300 24000	1900 4000	1	5	1	2	50 2500	2	0	0	0 300	0	0
1	88	98.87640449 100	1	15	1	4	24000	4000	0	0	0	2	400	2	0	0	100	0	300
1	89	98.87640449	1	8	1	1	400	800	1	1	1	1	400	2	0	0	100	100	200
1	85	95.50561798	1	10	1	4	15000	5000	1	4	1	1	0	2	0	0	200	600	800
0	71	79.7752809	1	5	1	2	500	300	0	0	0	2	200	2	0	0	100	0	100
0	74	83.14606742	1	12	1	6	5000	2000	1	1	1	1	0	2	0	0	0	0	0
0	83	93.25842697	1	5	2	6	2500	2500	3	3	2	1	0	2	0	0	250	500	750
0	73	82.02247191	1	8	1	2	3000	300	1	0	0	1		1	0	0	150	300	450
1	83	93.25842697	1	4	1	4	12000	3000	2	3	1	1	0	2	0	0	200	200	400
1	82	92.13483146	1	10	1	12	12000	3000	I	3	1	1	0	2	0	0	100	0	100
1	85	95.50561798	1	15	1	2	500	300	0	0	0	1	0	2	0	0	100	200	300
1	81	91.01123596	1	5	1	4	24000	7000	2	2	1	1	0	2	0	0	100	0	100
1	85	95.50561798	1	8	1	4	21000	5000	1	5	1	1	0	2	0	0	0	400	400
1	82	92.13483146	1	3	2	4	36000	8000	2	2	1	1	0	2	0	0	100	0	100
1	88	98.87640449	1	5	2	5	3600	1000	3	3	1	1	0	1	1	0	200	300	500
1	82	92.13483146	1	10	1	2	4000	3000	0	0	0	1	0	2	0	300	100	0	100
0	83	93.25842697	1	4	1	2	3000	0	0	0	0	1	0	2	0	0	100	150	250
1	74	83.14606742	1	5	1	2	2500	1600	2	1	1	1	0	2	0	0	0	0	0
1	84	94.38202247	1	10	1	5	3000	3000	2	3	1	1	0	2	0	0	0	50	50
1	87	97.75280899	1	3	1	1	0	0	0	0	0	2	100	2	0	0	100	0	100
1	85	95.50561798	1	7	1	1	500	300	0	0	0	1	0	2	0	0	100	50	150
1	80	89.88764045	1	7	1	2	10000	300	0	0	0	1	0	2	0	0	250	200	450
1	86	96.62921348	1	10	1	5	5000	4000	7	3	1	2	50	2	0	0	0	0	0
1	82	92.13483146	1	2	1	2	12,000	4000	4	3	1	1	0	2	0	0	100	0	100
1	75	84.26966292	1	5	1	2	20000	3000	7	4	1	2	100	2	0	0	0	0	0
1	86	96.62921348	1	10	1	4	35000	5000	2	3	1	1	0	2	0	0	200	0	200

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1 3 19700 1 <td>1</td> <td>84</td> <td>94.38202247</td> <td>1</td> <td>5</td> <td>1</td> <td>5</td> <td>13000</td> <td>5000</td> <td>0</td> <td>0</td> <td>0</td> <td>1</td> <td>0</td> <td>1</td> <td>2</td> <td>500</td> <td>0</td> <td>0</td> <td>0</td>	1	84	94.38202247	1	5	1	5	13000	5000	0	0	0	1	0	1	2	500	0	0	0
1 1	1	86	96.62921348	1	10	1	4	20000	6000	1	3	1	1	0	2	0	0	0	0	0
Image Image <th< td=""><td>1</td><td>86</td><td>96.62921348</td><td>1</td><td>4</td><td>1</td><td>1</td><td>5000</td><td>0</td><td>0</td><td>0</td><td>0</td><td>1</td><td>0</td><td>2</td><td>0</td><td>0</td><td>50</td><td>0</td><td>50</td></th<>	1	86	96.62921348	1	4	1	1	5000	0	0	0	0	1	0	2	0	0	50	0	50
1. 1. 1. 1. 1. 1. 1. 1. 1. 2. 1. 2. 3. 2. 3.	1	87	97.75280899	1	10	1	4	3000	1000	0	0	0	1	0	2	0	0	300	0	300
1 1 1 1 1 1 1 0 1 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0	1	86	96.62921348	1	5	1	4	5000	800	1	2	1	1	0	1	2	1000	400	600	1000
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18.Number of attendants accompanied in a single visit:	19. Average cost spent for transport of one attendant in a single visit (not considering the private or taxi cost)	20.Average cost spent for food of one attendant in a single visit	21.Total cost for food and transport of all attendants in single visit (excluding private transport and taxi)	22.Average number of days of work lost in a single visit:	23.Average loss of wages of one attendant during a single visit:	24.Total loss as lost wages	25. Any other expense for attending in person consultation apart from above mentioned cost	26.OPD ticket charge		28.total cost spent for a straight visit plus lost wages.	29.Number of Hospital admissions in last 6 months in AIIMS Jodhpur	30.No of Hospital admissions in other hospital	31.outside hospital admission- why 0-Not applicable, 1-No comments, 2- Financially better,3- Time saving, 4-Both		33.Total cost spent for any procedures during hospital admissions in last six months :	Investigations during	bed charges And	and Food of patient	¹ 37.Any outside Stay required or not for the attendants: 0-Not applicable ,1-no,2-yes
2	600	450	2100	2	500	1000	0	10	3410	4410	0	0	0	0	0	0	0	0	0
1	0	50	50	1	0	0	0	10	160	160	0	0	0	0	0	0	0	0	0
2	400	150	1100	2	300	600	0	10	2160	2760	0	0	0	0	0	0	0	0	0
1	500	150	650	2	400	800	0	10	1310	2110	2	0	0	1	0	900	0	600	1
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2	0	300	600 100	1	0	0	0	10	3410 610	3410 610	0	0	0	0	0	0	0	0	0
2	100	100	400	0	0	0	0	10	610	610	0	0	0	0	0	0	0	0	0
1	600	200	800	1	200	200	0	10	1610	1810	1	0	0	1	0	3000	0	700	1
1	0	100	100	1	200	200	0	10	410	610	0	0	0	0	0	0	0	0	0
2	250	150	800	1	200	200	0	10	810	1010	0	0	0	0	0	0	0	0	0
1	500	250	750	1	300	300	0	10	1510	1810	3	2	4	1	0	3000	3000	700	1
1	150	300	450	1	200	200	0	10	910	1110	0	0	0	0		0	0	0	0
1	200	200	400	1	300	300	0	10	810	1110	0	0	0	0	0	0	0	0	0
2	500	300	1600	1	500	500	0	10	1710	2210	1	5	4	1	0	800	7500	750	1
2	200	100	600	1	800	800	0	10	910	1710	0	0	0	0	0	0	0	0	0
1	250	150	400	0	0	0	0	10	510	510	0	0	0	0	0	0	0	0	0
1	400	0	400	1	300	300	0	10	810	1110	0	0	0	0	0	0	0	0	0
2	500	200	1400	1	300	300	0	10	1510	1810	1	0	0	2	0	4300	0	200	1
2	300	200	1000	2	300	600	0	10	1510	2110	0	0	0	0	0	0	0	0	0
2	500	0	1000	1	300	300	0	10	1410	1710	0	0	0	0	0	0	0	0	0
2	250	0	500	1	500	500	0	10	760	1260	0	0	0	0	0	0	0	0	0
2	400	150	1100	1	300	300	0	10	1110	1410	0	0	0	0	0	0	0	0	0
1	100	0	100	1	0	0	0	10	160	160	0	0	0	0	0	0	0	0	0
1	0	100	100	1	300	300	0	10	310	610	0	0	0	0	0	0	0	0	0
2	100	100	400	1	300	300	0	10	560	860	0	0	0	0	0	0	0	0	0
1	200	200	400	1	300	300	0	10	860	1160	0	0	0	0	0	0	0	0	0
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1	500	150	650	1	500	500	0	10	760	1260	0	0	0	0	0	0	0	0	0
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1 1	1	100	100	200	0	0	0	0	10	260	260	0	0	0	0	0	0	0	0	0
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38. If yes, Attendants stay at : relative's house (1) stay for rent (2).	39. Cost Spent for stay	40.Number of attendants accompanied in a single admission:	41.Average cost spent for transport, and Food of all attendants during hospital admission in last 6 months:	42.Number of days of work lost for one attendant in last 6 months due to hospital admission:		44.Total cost spent for Hospital admission in last 6 months	45. Total cost spent for hospital admission and as lost wages in last 6 months.	46.Cost spent for transportation for telemedicine required:	47.Total cost spent for registration and appointment for telemedicine	48.Wages lost for attending telemedicine consultation; if any:	49.Number of telemedicine consultation in the last 6 months?	50.Any additional cost for internet	51.Any other expense for attending t telemedicine consultation apart from above mentioned cost	52.Total cost spent for telemedicine services in last 6 months	53.Total Saving per telemedicine consultation	
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54.Total savings in 6 months	55.% Saving compared to income for last 6 months
8790	9.7666666667
590	1.18
2730	9.1
4220	16.88
370 3010	0.185
620	1.24
13610	3.888571429
600	0.24
560	0.28
7140	19.83333333
1190	3.9666666667
6010	20.03333333
10830	27.075
2220	7.4
4390	7.3166666667
26490	26.49
3420	2.28
2040	5.1
4390	8.78
7210	18.025
10520	21.04
3370	11.23333333
2520	2.52
2770	5.54
770	0.256666667
580	1.16
860	1.72
2220	5.55
5270	2.635
2470	2.47
820	1.64
16810	11.20666667

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56.Outcome	57.Out come score	58.In case of lost to follow up or treatment from outside; 0-Question not applicable Reason 1-Not able to contact patient at 6 months, 2- Reason not disclosed, 3- Personal reasons,4-They felt patient is disease free, 5- Not satisfied with treatment in AIIMS,6-Due to telemedicine service related issue	59.0-No worsening or no complication, 1- worsening but expected, 2- Complication or advrse event. (For lost to follow up patients their condition until follow up in AIIMS was considered.	60.In case of complication or adverse event the previous consulation was.0-Not applicable,1-opd visit,2-Telemedicine visit.	61.Travel distance saved in 6 months.
No further UTI episodes - On Antibiotic Prophylaxis	1	0	0	0	1200
Nephrotic syndrome 1 st episode progressed to SDNS- on levamisole , currently in remmission.	1	0	0	0	40
Currently asymptomatic according to parents. Stopped follow up as the Patient is asymptomatic	1	0	0	0	300
received 2 doses of inj cyclophosphamide currently, Urine protein 3+ Currently on persistent remmission on MMF	2	0	1 0	0	1140 60
In Remmission	1	0	0	0	500
Remmission	1	0	0	0	8
Completed Tb Treatment, Currently not in active disease	1	0	0	0	1600
currently asymptomatic, as the baby become asymptomatic after taking drugs, they didnt continue with the advised investigations	1	0	0	0	60
Child is not having any acute issue, symptoms resolved.	1	0	0	0	150
Patient is started on MMF, levanisole was stopped , Antithrombotic trreatment was stopped after MRI- Currently in remnission	2	0	1	0	1200
Currently in remmission	1	0	0	0	240
There was partial remmission, plan to start Cyclophosphamide	2	0	1	0	1080
Completed total of seven doses of cyclophosphamide, currently in remmission	1	0	0	0	3000
They stopped treatment by themselves-reason given was, child is asymptomatic, and is not having any issue for the last 4 months after stopping medication.	1	4	0	0	360
Curently on control on steroid and HCQ	1	0	0	0	640
In remmission -completed 6 doses cyclophosphamide	1	0	0	0	4800
In remmission-No relapse in last 6 months.	1	0	0	0	280
SRNS -Partial remmission on Tacrolimus, MMF, steroids, completed 3 years of Tacrolimus- Planned for inj Rituximab	2	0	1	0	800
Patient in remmission on tacrolimus, and steroids(Tapering)	1	0	0	0	1600
Currently in remmission on cyclopsporine and tapered dose of labetalol, BP under control with on admission in between due to SBP	2	0	2	2	1600
Currently asymptomatic ,anti hypertensives and anti epileptics - stopped	1	0	0	0	3000
Patient is on treatment from outside hospital, as there was issue with appointment and also was not completely satisfied with the srvice as though initially after 1 month month of first consultation was adjustable.Patient is asymptomatic	1	6	0	0	480
Have stopped medicines by themselves, according to them the child is asymptomatic for the last 6 months	1	4	0	0	320
Currently on medicines , asymptomatic , on follow up	1	0	0	0	800
Patient is on follow up, hypertension under control on on same drugs.	1	0	0	0	80
Patient is asymptomatic not on follow up	1	4	0	0	60
Patient is in remmission, not on steroids	1	0	0	0	200
Patient is in susained remmission, currently not on any immunosuppressives, on envas	1	0	0	0	800
Hypertension is under control on drugs, was not able to taper, no renal artery	1	0	0	0	30
stenosis no worsening of KFT. In partial remmssion on tacrolimus and steroids	2	0	1	0	760
Patient expired in december 2021-1 st)-SRNS with Complicated relapse-volume	3				
overload with AKI with sepsis. Patient is currently in Remmission, steroid tapered, labetalol was stopped and		0	2	1	40
dose of thyroxine was also tapered.	1	0	0	0	2000

Cyclosporine levels were hiked according to levels , currently the patient is in	1	0	0	0	3000
remmission hypertension under control					
Re0l Function is static and no hypertensive records on home BP monitoring stopped follow up as the childs father got ill took medicines for 4.5 months	1	0	0	0	2000
stopped follow up as the childs father got ill, took medicines for 4-5 months, not on any medications for the last one month and according to mother the child is asymptomatic	1	3	0	0	80
Child is in remmission on levamisole, hypertension under control , tapered drugs	1	0	0	0	2800
Patient had one relapse in september on above drugs. Was started on full dose steroids.currently in remnission.	1	0	0	0	2000
Was not able to have follow up visits as her uncle was out of station, was taking drugs according to last prescription, waqs monitoring BP and is under control,	1	3	0	0	600
have not done any repeat investigations					
Patient is in Remission off steroids off antihypertensives	1	0	0	0	96
Patient had one Relapse in between, currently in remmission and not on any steroids	1	0	0	0	1200
Patient is in remmission.But stopped levamisole by themselves.	1	4	0	0	960
0	0	0	0	0	0
Treatment from outside hospital.Patient is currently asymptomatic, renal Biopsy was done, which showed FSGS, Patient had CSVT, associated with Relapse treated with anticoagulation currently asymptomatic and in Remnission.	1	2	2	1	120
Child is in sustained Remmision on Levamisole, Steroids were stopped in Telemedicine visit	1	0	0	0	1000
Kidney function is static, hypertension under control	1	0	0	0	1600
remmission	1	0	0	0	500
Patient is in sustained remmission on levamisole(started in June) and alter0te day steroids	1	0	0	0	4800
Disease activity is under control on HCQ and aler0te day steroids, MMF was stopped gangrene is improving.	1	0	0	0	1500
Patient is currently admited in ward in relapse with AKI.	2	0	2	2	880
Patient had a relapse in between in september, but currently in remmission on alter0te day steroids and levamisole.	1	0	0	0	200
Currently on UTI Prophylaxis -no active issues	1	0	0	0	10
VUR grade 4 ,no further UTI ,no worsening of kidney function	1	0	0	0	2800
Patient is not having any issues , no hematuria, no proteinuria, on steroids and MMF, completed 6 doses of cyclophosphamide and BP under control on AmnIodipine	1	0	0	0	1120
Patient developed nephrotoxicity to tacrolimus and so tacrolimus was stopped and was started on inj cyclophosphamide currently in remission.	2	0	2	2	320
Currently CKD stage 5 Planning for re0l transplant	2	0	1	0	48
Patient is in remission, tapered and stopped steroids They have stopped the treatment as patient was asymptomatic. Currently also	1	0	0	0	72
the patient is not having any symptoms. Patient had undergone 3 procedures in last 6 months, currently patient is	1	4	0	0	180
asymptomatic, prophylaxis stopped.	1	0	0	0	600
Patient is in remission on Levamisole	2	0	1	0	230
CKD stage 5 - No further UTI or Hospital admission	1	0	0	0	1000
No further UTI - on prophylaxis, KFT static	1	0	0	0	400
Patient is in remmission , on follow up Patient had one more relapse , but currently in remmission on MMF 0d low	2	0	0	0	1600 800
dose steroids. Patient is now on trestment from outside doctor. Attendant told he is not comfortable with telemedicine , no clear reason given , and he have to spent much time for getting consultation from aiims.Currently child is in remmission reason in the transmit due to heave most the transmits.	1	6	0	0	32
on outside treatmnet , dont know , what medicines. Patient is in remission , not on any drugs, after the last relapse	1	0	0	0	30
Patient is still having nocturia, frequency decreased, was advised regarding alarms and other conservative measures from AIIMS	1	2	0	0	60
0	0	0	0	0	0
CKD stage 5 - Hypertension under control on AMLODIPINE , LABETALOL AND PRAZOSIN with one episode of Hypertensive urgency	2	0	2	2	500
Patient is in sustained Remmission.	1	0	0	0	1000
Currently in remmission , not on any drugs	1	0	0	0	240
Hypertension under control on Amlodipine and KFT static	1	0	0	0	180
patient is on follow up , no worsening , no active issues Patient is on routine follow up , no futher worsening or any active issues.	1	0	0	0	80 80
Currently patient is not on any drugs, in remmission.	1	0	0	0	480

Patient just had 3 visits in AIIMS, medicines were taken for one month and then					
they are in treatment from outside hospital	0	2	0	0	920
Patient was on levmisole, had relapse and so was started on MMF	2	0	1	0	200
Child had one more relapse - last in december - currently in remmission	1	0	0	0	500
0	0	0	0	0	0
No further fracture or disease progreassion	2	0	1	0	40
In remmission.	1	0	0	0	360
in renamission.		0	0	Ū	500
Levamisole was stopped in march , had relapse in june started on full dose steroids , acheived remmision , and one more relapse , so started on tacrolimus.	2	0	1	0	100
Patient is currently asymptomatic nothing found abnormal on evaluation	1	0	0	0	1050
One more relapse in 6 months, currently in remission.	1	0	0	0	1500
Patient taking treatment from outside hospital - No further UTI not on any drugs.	1	2	0	0	160
Currently on low dose alternate day steroids in remmission	1	0	0	0	16
SDNS on low dose alternate day steroids - in sustained remmission.	1	0	0	0	160
	I		-	-	
Still in remmission	1	0	0	0	20
Patient in remission- follow up after dengue.	1	0	0	0	360
Patient is on UTI prophylaxis - no further UTI	1	0	0	0	24
Patient was initially on full doe steroids, changed to alter0te day after 6 weeks as the patient was in remmission, and then gradually tapered as the biopsy was showing FSGS	1	0	0	0	1600
Patient is in sustained remission remission on LTAD steroids	1	0	0	0	140
Patient is started on MMF as she was high dose steroid dependant and currently in remmission.	2	0	1	0	48
No further episodes of fever, no worsening of KFT.	1	0	0	0	24
Patient was in stage 2 CKD worsened to stage 3	2	0	1	0	520
Patient is in remmission, hypertension under control.	1	0	0	0	250
Hypertension is under control on same dose of drugs	1	0	0	0	32
In remmission	1	0	0	0	60
child is in remmission	1	0	0	0	320
Patient is on UTI prophylaxis.No breakthrough UTI. No worsening of kidney					
function	1	0	0	0	560
Patient is in remmission on levamisole- steroid dependent nephrotic syndrome	1	0	0	0	3600
No worsening of kidney function, no episodes of decompensation hypertension under control	1	0	0	0	300
No acute worsening in last 6 Months.Hypertension under control	1	0	0	0	1080
Patient was initially treated for relapse, but was frequently relapsing and so levamisole was started and currently in remmission.	2	0	1	0	1400
ssns -ifrns - in remnission	1	0	0	0	1000
Stopped treatment due to personal reasons, but asymptomatic	1	4	0	0	400
one episode of simple UTI with E coli , trested with oral antibiotics. No h/o					
decreased urine output or any other episodes of UTI.	2	0	1	0	32
Patient is asymptomatic, without stunting ht 149 cm	1	0	0	0	12
	1	0	0	0	360
Patient had undergone planned diverticulostomy, No worsening of Kidney	1	0			
Function, hypertension under control				0	200
	1 1 2	0	0	0	200