

Implementation, Patient Satisfaction and Usability of Telemedicine Services for Pediatric Thalassemia Cases in Balochistan During COVID-19 Pandemic and Beyond

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Abstract: *Background:* Telemedicine health service has revolutionized delivery of health care to the doorsteps of needy and deserving cases especially since the onset of the recent pandemic; COVID-19. Beta thalassemia major children require lifelong medical care, despite any untoward circumstances. Aim of this study is to identify role of telemedicine in diagnosing, treating and following-up of thalassemia cases and assess patient satisfaction. *Objective:* To assess implementation, patient satisfaction and usability of telemedicine health service for pediatric thalassemia cases in Northern Balochistan. *Study place and duration:* Study was carried out at District Headquarter Hospital Zhob from April 2021 to September 2021. *Material & methods:* Telemedicine service was established at Pediatric Department DHQ Hospital Zhob during COVID-19 pandemic. The data of all thalassemia cases that were managed/provided health care via telemedicine was collected and recorded. Patient satisfaction and usability of telemedicine service provided was assessed using a questionnaire prepared after thorough study of literature. The parents and care-givers of thalassemia cases treated via telemedicine were interviewed on mobile cell phones/telephone and the questionnaires were filled. Overall satisfaction was also gauged according to a scale from 1 to 5, where 1 depicted extremely dissatisfaction and 5 showed extreme satisfaction. The data was analyzed with Statistical package for social science (SPSS 21). *Results:* Total 347 patients of thalassemia received telemedicine health service during the study period. There were 182 (52.4%) males and 165 (47.6%) females with age range of 1 – 15 years (mean age 8.09 + 3.47 years). Total 289 (83.3%) telemedicine service seekers were residing in rural areas and rest 58 (16.7%) resided in urban areas. Ninety seven families (28%) belonged to poor class, 192 (55.35) belonged to lower middle class, 55 (15.9%) belonged to upper middle class and 3 (0.9%) belonged to rich class. Majority of participants (97.4%) were significantly satisfied with telemedicine service (p value 0.001). *Conclusion:* During current COVID-19 pandemic telemedicine has emerged as an exceptional alternate mode of healthcare delivery. It saves cost and time of travelling for thalassemia cases who require life-long hospital visits and follow-up. People have shown high satisfaction and positive attitude towards telemedicine health service provision.

Keywords: Satisfaction, Telemedicine, Thalassemia, Pediatric

1. Introduction

The global pandemic of COVID-19 brought up unprecedented challenges to the healthcare system worldwide. Lockdowns, unavailability of transport, fear of acquiring COVID-19 drastically affected human lives especially their health [1]. People with chronic ailments requiring regular hospital visits and follow-up were neglected and at risk of

relapsing and developing complications. Thalassemias are hereditary disorders appearing early in life and progressing gradually. Thalassemia is the most frequent hemoglobinopathy resulting from imbalanced globin chain synthesis leading to destruction of red blood cells causing anemia and peculiar set of clinical findings [2]. This disease is prevalent world-wide especially in Mediterranean, Middle East and Asian descent [3]. Thalassemia patients require

frequent hospital visits and physician consultation to maintain their hemoglobin level, monitor ferritin levels and achieve other biochemical homeostasis. Failure to do so can eventuate to catastrophe. In Pakistan, prevalence of hemoglobinopathies has been reported 0.79% in population of North Balochistan region. Beta thalassemia major was found to be most frequent (29.4%), followed by sickle/beta thalassemia heterozygous disease (28.3%) and sickle cell anemia (28%) [4]. Thalassemia, being a chronic disease, is associated with many co-morbidities and complications including diabetes, pulmonary hypertension and heart failure leading to increased risk of severe COVID-19 and 5 fold increase in lethality due to COVID-19 infection [5].

Telemedicine is defined as “a service that helps to improve a patient’s health through two-way, real time interaction between physician and patient at a distant site” [6]. It has proved efficient and cost effective during the recent pandemic [7]. Telemedicine emerged in ancient times in the form of smoke signals to warn about sickness in the nearby cities [8]. Over the past few decades, use of telemedicine has advanced greatly because of digital development. In 1990’s, mobile phones and internet became widely available and provided platform for future of telemedicine. In Pakistan, according to a recent survey, 81% of adult males and 38% of adult females own mobile phones [9]. This shows increasing trend of using and accessibility of mobile phone by majority of adult population. This technology has made telemedicine quite easier, with help of which X-rays, laboratory investigations can be shared along with online consultation with physicians.

During COVID-19, telemedicine has been used extensively to manage patients at home not only of COVID-19 disease (mild disease) but also other various diseases (respiratory, dermatologic, cardiovascular, psychological etc) effectively and efficiently to avoid disease exposure and reduce burden on health facilities [10].

Patient satisfaction is an essential indicator to measure quality in health care [11]. It helps improve clinical outcome and alleviate malpractice. In brevity, it measures success of health care. Feedback given by the patients goes a long way

in boosting healthcare delivery. We carried out this study to assess the implementation, patient satisfaction and usability of telemedicine services to the cases of thalassemia in the areas of high prevalence in Northern Balochistan.

2. Material and Methods

The study was carried out at District Headquarter Hospital Zhob from April 2021 to September 2021. Telemedicine service was established at Pediatric Department DHQ Hospital Zhob during COVID-19 pandemic to reduce patients’ burden on hospital and avoid risk of transmission of COVID-19. Placards were displayed at prominent places and patients were informed to contact on given mobile phones for health care consultation.

The data of all thalassemia cases that were managed/provided health care via telemedicine was collected and recorded. Permission was obtained from ethical committee of the hospital and the consent was taken from the care givers and parents of thalassemia patients. Similarly, the patients who were diagnosed/suspected as case of thalassemia during hospital visits were advised to follow-up via telemedicine.

Inclusion criteria;

All the pediatric cases of thalassemia (<15 year age) who were managed through telemedicine (mobile phones and whatsapp) were included.

Exclusion criteria;

The cases who lost to follow up or who did not consent for inclusion in the study were excluded.

The thalassemia cases were provided treatment via telemedicine accordingly. The protocol of investigations followed is shown below in Table 1. It was formulated after detailed study of literature. The patients were advised laboratory investigations, and on subsequent telemedicine visit they were advised treatment according to the investigations in addition to thorough history. The anthropometric measurements of thalassemia cases required (height, weight, head circumference) were carried out by the parents/care givers and noted by the physician.

Table 1. Schedule of investigations and measurements of thalassemia patients.

S/No.	Laboratory test and measurement	Ages	Frequency
1	CBC with differential, LFTs, RFTs	All ages	1. Monthly in transfusion dependent patients 2. 6 monthly in non-transfusion dependent
2	Transfusion/Chelation history	All ages	Monthly
3	Serum ferritin	All ages	3 monthly
4	HbSAg, Anti HCV antibodies, HIV	All ages	Once a year
5	Ultrasound liver	All ages	Once a year
6	Echocardiogram	>10 years	Once a year
7	TSH, T4, PTH, Vitamin D level	>6 years	Once a year
8	FSH, LH, Testosterone and Estradiol levels	>10 years	Once a year
9	Tanner Stage	>10 years age	6 monthly
10	Height, weight, head circumference, truncanl height	All ages	Annual 3-6 monthly during puberty and in transfusion dependent patients

CBC: Complete blood count; LFTs: Liver function tests; RFTs: Renal function tests; HbSAg: Hepatitis B surface antigen; Anti HCV: Antibodies to hepatitis C virus; HIV: Human immunodeficiency Virus; FSH: follicle stimulating hormone; LH: Luteinizing hormone; TSH: Thyroid Stimulating hormone; T4: Thyroxine hormone; Tanner stage (sexual maturing rating system).

Patient satisfaction and usability of telemedicine service provided was assessed using a questionnaire prepared for this purpose (Table 2). It was formulated after thorough study of literature. Questionnaires consisted of all relevant questions/items as shown below. The parents and care-givers of thalassemia cases treated via telemedicine who

consented for subject assessment were interviewed on mobile cell phones/telephone and the questionnaires were filled. Overall satisfaction was also gauged according to a scale from 1 to 5, where 1 depicted extremely dissatisfaction and 5 showed extreme satisfaction (Row 11, Table 2).

Table 2. Patient satisfaction & usability Questionnaire.

S/No	Patient satisfaction & usability (Questionnaire items)	Yes	No
1	Could you hear your physician well?		
2	Could your physician hear you well?		
3	Was it convenient using telemedicine for you?		
4	Were you comfortable communicating with the physician?		
5	Did your physician understand the healthcare concerns of your patient?		
6	Did you receive adequate attention from your physician regarding your thalassemia patient?		
7	Did telemedicine health service address health care needs of your thalassemia patient?		
8	Did telemedicine service save your time?		
9	Did telemedicine service save you expense of travelling?		
10	Will you use telemedicine service again ?		
11	What was your overall satisfaction with the telemedicine consultation?		
	Extremely dissatisfied ← 1 2 3 4 5 → Extremely satisfied		

All the data including; number of thalassemia cases who received telemedicine service, their age, gender, residence (rural or urban), socioeconomic status (poor, lower middle class, higher middle class, and rich), education status of father (uneducated, primary educated, matriculate, graduates), education status of mother (uneducated, primary educated, matriculate, graduates) and the information obtained through interviews for assessing patient satisfaction and usability was analyzed with statistical package for social science (SPSS 21). Chi square was used to analyze qualitative variables like gender, education status and socioeconomic status etc and independent t test was used to compare quantitative variables like age. P value < 0.05 was considered significant.

Total 347 patients of thalassemia received telemedicine health service during the study period. There were 182 (52.4%) males and 165 (47.6%) females with age range of 1 – 15 years. Mean age was 8.09 + 3.47 years. Out of the total, 266 fathers (76.75) made contact for telemedicine health service, 19 mothers (5.5%) and 62 (17.9%) care-givers contacted. Total 289 (83.3%) telemedicine service seekers were residing in rural areas and rest 58 (16.7%) resided in urban areas. Ninety seven families (28%) belonged to poor class, 192 (55.35) belonged to lower middle class, 55 (15.9%) belonged to upper middle class and 3 (0.9%) belonged to rich class as shown below. Rest of the demographic properties have been shown in Table 3.

Table 3. Demographic properties of cases.

S/No	Demographic property	N	%age
1	Gender		
	Male	182	52.4%
	Female	165	47.6%
2	Age		
	1-15 years	8.09 + 3.47	
3	Person contacted for Telemedicine service		
	Fathers	266	76.7%
	Mother	19	5.5%
	Care-giver	62	17.9%
4	Residence		
	Rural	289	83.3%
	Urban	58	16.7%
	Poor	97	28%
5	Socioeconomic status		
	Lower middle class	192	55.3%
	Upper middle class	55	15.9%
	Rich	3	0.9%
	Uneducated	87	25.1%
6	Education status father		
	Primary qualified	125	36%
	Matriculate	130	37.5%
	Bachelor	5	1.4%
	Uneducated	254	73.2%
7	Education status mother		
	Primary qualified	83	23.9%
	Matriculate	9	2.6%
	Bachelor	1	0.3%

3. Results

Demographic properties of both rural and urban participants were also compared as shown in Table 6 below. There was significant difference between persons who

contacted for telemedicine consultation between rural and urban participants (P value 0.002), and socioeconomic status of rural versus urban participants (p value 0.006) as shown in Table 4.

Table 4. Comparison of demographic properties of both rural and urban participants.

S/No	Demographic property		Rural	Urban	Total	P value
1	Gender	Male	152 (83.5%)	30 (16.5%)	182 (52.4%)	0.904
		Female	137 (83%)	28 (17%)	165 (47.6%)	
		Total	289 (83.3%)	58 (16.7%)	347	
2	Age	Years	7.93 + 3.45	8.90+3.53	8.09 + 3.47	0.05
		Fathers	230 (85.5%)	39 (14.5%)	269 (77.5%)	
		Mother	9 (52.9%)	8 (47.1%)	17 (4.9%)	
3	Person contacted for Telemedicine service	Care-giver	50 (82%)	11 (18%)	61 (17.6%)	0.002
		Total	289 (83.3%)	58 (16.7%)	347	
		Poor	88 (90.7%)	9 (9.3%)	97 (28%)	
4	Socioeconomic status	Lower middle class	161 (83.9%)	31 (16.1%)	192 (55.3%)	0.006
		Upper middle class	38 (69.1%)	17 (30.9%)	55 (15.9%)	
		Rich	2 (66.7%)	1 (33.3%)	3 (0.9%)	
5	Education status father	Total	289 (83.3%)	58 (16.7%)	347	0.532
		Uneducated	70 (80.5%)	17 (19.5%)	87 (25.1%)	
		Primary qualified	109 (87.2%)	16 (12.8%)	125 (36%)	
6	Education status mother	Matriculate	106 (81.5%)	24 (18.5%)	130 (37.5%)	0.828
		Bachelor	4 (80%)	1 (20%)	5 (1.4%)	
		Total	289 (83.3%)	58 (16.7%)	347	
		Uneducated	209 (82.3%)	45 (17.7%)	254 (73.2%)	
		Primary qualified	71 (85.4%)	12 (14.6%)	83 (23.9%)	
		Matriculate	8 (88.9%)	1 (11.1%)	9 (2.6%)	
		Bachelor	1 (100%)	0	1 (0.3%)	
		Total	289 (83.3%)	58 (16.7%)	347	

Out of total 347 patients attended through telemedicine service, 305 (87.9%) consented for the interviews and survey. Out of total 305, 93.4% respondents were satisfied with the conversation / hearing their physician, 93.8% responded that physician could hear them well, 98% declared telemedicine service very convenient to use, 98.7% were very comfortable while using telemedicine service and 94.4% responded that the physician could understand their concern easily. 95.7% respondents were confident that the physician gave adequate attention to the patient. 98.7% responded that telemedicine

service addressed their health care need. Ninety eight percent respondents said that telemedicine service saved them time and expenses. All (100%) wished to use telemedicine in future. Comparison of satisfaction between rural and urban population has been elaborated in Table 5 below. There was no significant difference between the questionnaire items between the two groups (rural and urban) except saving travelling expenses which was significantly more in rural respondents (p=0.014).

Table 5. Patients' satisfaction and usability & comparison between rural and urban respondents.

S/No	Patient satisfaction & usability (Questionnaire items)		Rural Respondents	Urban respondents	Total	P value
1	Could you hear your physician well?	Yes	242 (84.9%)	43 (15.1%)	285 (93.4%)	0.535
		No	18 (90%)	2 (20%)	20 (6.6%)	
		Total	260 (85.2%)	45 (14.8%)	305	
2	Could your physician hear you well?	yes	243 (85%)	43 (15%)	286 (93.8%)	0.592
		No	17 (89.5%)	2 (10.5%)	19 (6.2%)	
		Total	260 (85.2%)	45 (14.8%)	305	
3	Was it convenient using telemedicine for you?	Yes	254 (84.9%)	45 (15.1%)	299 (98%)	0.303
		No	6 (100%)	0	6 (2%)	
		Total	260 (85.2%)	45 (14.8%)	305	
4	Were you comfortable communicating with the physician?	yes	256 (85%)	45 (15%)	301 (98.7%)	0.402
		No	4 (100%)	0	4 (1.3%)	
		Total	260 (85.2%)	45 (14.8%)	305	
5	Did your physician understand the healthcare concerns of your patient?	Yes	246 (85.4%)	42 (14.6%)	288 (94.4%)	0.729
		No	14 (82.3%)	3 (17.7%)	17 (5.6%)	
		Total	260 (85.2%)	45 (14.8%)	305	

S/No	Patient satisfaction & usability (Questionnaire items)	Rural Respondents	Urban respondents	Total	P value
6	Did you receive adequate attention from your physician regarding your thalassemia patient?	Yes 251 (86%)	41 (14%)	292 (95.7%)	0.096
	No	9 (69.2%)	4 (30.8%)	13 (4.3%)	
	Total	260 (85.2%)	45 (14.8%)	305	
7	Did telemedicine health service address health care needs of your thalassemia patient?	Yes 257 (85.4%)	44 (14.6%)	301 (98.7%)	0.561
	No	3 (75%)	1 (25%)	4 (1.3%)	
	Total	260 (85.2%)	45 (14.8%)	305	
8	Did telemedicine service save your time?	Yes 255 (85.3%)	44 (14.7%)	299 (98%)	0.894
	No	5 (83.3%)	1 (16.7%)	6 (2%)	
	Total	260 (85.2%)	45 (14.8%)	305	
9	Did telemedicine service save you expense of travelling?	Yes 257 (86%)	42 (14%)	299 (98%)	0.014
	No	3 (50%)	3 (50%)	6 (2%)	
	Total	260 (85.2%)	45 (14.8%)	305	
10	Will you use telemedicine service again?	Yes 260 (85.2%)	45 (14.8%)	305 (100%)	-
	No	0	0	0	
	Total	260 (85.2%)	45 (14.8%)	305	

Overall patient satisfaction with telemedicine health service was significant ($P=0.001$); 55.1% respondents were extremely satisfied, 42.3% were satisfied and 2.6% were

neutral. No respondent was dissatisfied with telemedicine service provided to them as shown table 6 below.

Table 6. Overall Patient Satisfaction with Telemedicine Service.

Satisfaction	Grade	Rural Respondents	Urban respondents	Total	P value
Overall satisfaction with telemedicine service	Extremely satisfied	152 (90.5%)	16 (9.5%)	168 (55.1%)	$P=0.001$
	Satisfied	104 (80.6%)	25 (19.4%)	129 (42.3%)	
	Neutral	4 (50%)	4 (50%)	8 (2.6%)	
	Total	260 (85.2%)	45 (14.8%)	305	

4. Discussion

Telemedicine health service has been in practice for quite some time. It is efficient, time saving and effective mode of healthcare delivery [12]. Its use enhanced a lot during current pandemic of COVID. It was used efficiently for COVID-19 infection so that cases with mild or asymptomatic disease could be managed at home giving relief to already scrambled and choked health care system during COVID-19 pandemic [7]. Other diseases including cardiovascular, dermatological, neurological, psychological diseases etc were also managed through telemedicine. Researchers have shown that radiologists, psychiatrists and cardiologists use telemedicine extensively at rates of 39.5%, 27.8% and 24.1% respectively [13].

Our study stands out from other studies in being unique with regards to providing telemedicine health care to thalassemia children, as no other study has been carried out in this particular field. In our study, 347 thalassemia cases were provided telemedicine health care services during pandemic. Out of these, 87.9% consented for survey of patient satisfaction and usability of telemedicine healthcare service. Majority of respondent (97.4%) expressed significant satisfaction with telemedicine mode of health care delivery ($p=0.001$), where as remaining 2.4% were neutral. Telemedicine service saved travelling time and travelling expense, expressed by 98% of participants.

Balochistan has a vast area with majority of population living in rural, far flung areas with very poor road infrastructure [14]. People have to travel for hours to reach

the health facilities located in the urban areas, especially the DHQ Hospital. Telemedicine saves the patients not only travelling time but also travelling expenses. Studies have shown that travel cost is a serious hurdle to seek timely healthcare [12, 15]. Telemedicine has not only addressed this issue of travelling cost but also loss of time incurred.

Our findings match the results shown by Kaur et Al., who showed that respondents expressed 84-100% agreement to telemedicine health service provided for management of hyperthyroidism [16]. Similarly other researchers also have shown high satisfaction of patients who used telemedicine health service during pandemic [17-19].

Need of the hour is implementation of telemedicine health services by various specialties and form modalities and guide-lines for various diseases accordingly. This can help save time, cost, and resources not only for patients but also health care providers. Telemedicine service provided during pandemic should continue to be delivered beyond the era of pandemic to maximize health care delivery especially for those living in remote or far lung areas.

5. Conclusion

During current COVID-19 pandemic telemedicine has emerged as an exceptional alternate mode of healthcare delivery. It saves cost and time of travelling for thalassemia cases who require life-long hospital visits and follow-up. Telemedicine health services have improved outreach and facilitated thalassemia children a lot. People have shown high satisfaction and positive attitude towards telemedicine health service provision. Therefore, telemedicine should be made an

important tool for providing medical services to deserving cases especially thalassemia children.

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