

Quality of Life & Associated Factors in Children Having Polio Related Disabilities; A Cross Sectional Study

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Author's Contribution

¹⁻³Conception and design, Collection and assembly of data, ²⁻⁶Analysis and interpretation of the data, ³⁻⁵Critical revision of the article for important intellectual content, Statistical expertise ¹⁻⁶Final approval and guarantor of the article

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ABSTRACT

Objectives: To determine the Quality of life & its association with clinico-demographic variables of post-poliomyelitis children having disabilities.

Methodology: This cross sectional study recruited N=460 post-polio cases from Khyber Pakhtun Khwa and Khyber Pakhtun Khwa Tribal District from July 2019 to December 2019 using convenience sampling. Sample included both genders, aged 15 years or less, who had received rehabilitation services for more than 3 months & had a valid case identification number. Cases who did not receive rehab in the last 2 months, those having other health related issues or impairments along with polio were excluded from the study. Basic demographic sheet and World Health Organization Quality of Life questionaire on disability was used for the data collection and analysis done using SPSS Version 21.

Results: Study revealed highest domain score for psychological $(13.11\pm2.19/56.85\pm13.43)$ followed by physical $(12.74\pm2.78/55.07\pm16.85)$ and environmental $(12.31\pm2.06/53.03\pm13.08)$ domains, the least score was of social domain $(10.67\pm2.14/41.81\pm13.34)$. Quality of life revealed significant association (p<0.001) with occupation, visibility of disability, disability affecting life; and its physical domain with Age of onset & duration (p=0.026); physical (p=0.003), psychological (p=0.000) and environmental (p=0.000) domain with income.

Conclusion: The quality of life of post-polio cases with disabilities in Khyber Pakhtunkhwa & its Tribal District is compromised with highest domain score for psychological followed by physical and environmental domains, the least score was of social domain. Quality of life revealed significant association with occupation, visibility of disability, disability affecting life; and its physical domain with Age of onset & duration; physical, psychological and environmental domain with income.

Key Words: Disability, Poliomyelitis, Polio Rehabilitation Initiative, Quality of life.

Introduction

Poliomyelitis is a paralytic & highly infectious disease caused by a virulent virus from the Picornaviridae family. It is one of the oldest diseases and has been mentioned in Egyptian drawings as well.¹ It affects mostly children aged less than 5 years through individual to individual contact and gains access to human body through fecal-oral route, multiplies in the gastrointestinal tract from where it is excreted infecting others.²

Poliomyelitis is characterized by clinical signs and symptoms which vary from mild respiratory symptoms including fever, headache, fatigue, Gastro-intestinal involvement like vomiting; to severe form of disease involving the nervous system resulting in paralysis.^{1, 2}

Literature reveals a high prevalence of polio survivors of 165/100000 person-year in countries with high income and an even higher prevalence of 425 per 100000 person-year in lower and middle income countries.³ Despite successful global efforts at eradication wiped out polio from most of the countries of the world leaving behind Nigeria, Afghanistan and Pakistan in 2013, where polio was endemic.1 Of the three types of wild poliovirus (WPV) type 2 and type 3 have been reported to be eliminated, however type 1 remains the sole WPV causing disability and still detected in Paksitan and Afghanistan⁴ with 198 cases from Pakistan & 80 from Afghanistan reported in 2011.5 In Pakistan Polio is still encountered in metropolitan city of Karachi, Quetta and adjoining areas of Pishin and Killah Abdullah, FATA & Peshawar where low socioeconomic status, lack of knowledge of hazards of polio virus and disinformation regarding vaccine are contributing to persistence of virus.⁵ Fortunately Pakistan is gaining success by reducing the number of cases in recent years from 147 for 2019 and 84 for 2020 and so on.⁶

Compared to general population, WPV affected patients who survive with post-polio syndrome suffer poorer functional and physical level with anxiety and depression; issues with mobility and even worse quality of life in those with associated pain and fatigue.⁷

Polio Rehabilitation Initiative (PRI) with funding from International Islamic Relief Organization (IIRO) and Bill & Melinda Gates Foundation (BMGF) has provided comprehensive rehabilitation to children with Post-Polio syndrome (PPS) cases including inclusive education as well.⁸

Quality of life (QoL) measurement is important for cases of PPS which needs research ⁹. Surviving Polio cases result in medical issues and pose rehabilitative, social and education related challenges for decades.¹⁰ Also according to Ganesh GS et al. screening all patients with PPS for fatigue and low physical activity, devices being used and determining its effects on QoL is essential, so that a variety of interventional treatments to minimize fatigue can be used as soon as possible.¹¹ Hence, knowledge in physical domains related to polio surviving patients can assist in prioritizing services and operations for this population.¹¹

Therefore keeping in view the prevalence of post-polio cases, need to study their quality of life with a goal of rehabilitation and need of research in the field⁹, hence current study was conducted with the objective to determine the Quality of life & association with clinic-demographic variables of post-poliomyelitis children having disabilities. The study is of

significant importance, since it will help better rehabilitate these post-polio cases and add essential data to act as a base for future research.

Methodology

This cross sectional study was conducted in Khyber Pakhtunkhwa (KPK) and Khyber Pakhtunkhwa Tribal District (KPTD) over a period of 6 months from 1st July 2019 to 31st December 2019. Study recruited a sample of N=460 diagnosed Polio affected cases duly identified and notified by World health Organization and had received rehabilitation services through Polio Rehabilitation Initiative (PRI) Project for more than 3 months using non-probability convenience sampling. Sample included both genders, aged 15 years or less with valid EPID number and relevant details. Patient data of cases was collected from federal and provincial offices of World Health Organization (WHO) in Pakistan. Cases who did not receive rehabilitation services in the last 2 months, those having other health related issues or impairments along with polio and those who migrated were excluded from the study. Sample size of N=461 was calculated using Raosoft online calculator with 97% confidence level & 5% margin of error & a population size of 20000. Cases who did not consent for inclusion in study were excluded, hence a sample of N=460 patients who fulfilled selection criteria were included in the study.

Study was conducted after obtaining ethical approval of the research from Institutional Research Board of Isra University, Islamabad vide registration number (1709-M.Phil P& O-007).

Sample population was contacted via phone and invited to participate in the study, however in KPTD areas where communication system was not yet established especially in North Waziristan and Khyber, visits were arranged with government and WHO staff working in the region and face to face interviews were arranged.

Basic demographic sheet and WHO Quality of Life questionaire on disability (WHOQOL-BREF Field Trial Version) was used for the data collection. The WHOQOL-BREF (Field Trial Version) is a 26 item version with four distinct domains of physical, social, environmental and psychological issues, and has excellent psychometric features of dreliability as well as validity.¹²

Higher domain scores denote higher quality of life and lower scores lower QoL. The mean score of items within each domain is used to calculate the domain score. To make it comparable with the scores of WHOQOL-100, mean scores are then multiplied by 4 and subsequently transformed to a 0-100 scale. Data was entered in Microsoft Excel and analyzed utilizing SPSS Version 21. Descriptive analysis was utilized and frequency, percentage and mean scores were calculated. T-test and ANOVA statistics were used to see any associations. P<0.05 was considered significant.

Results

In Current study with a sample of N=460 (Table I) majority of cases 260(56.5%) were males and remaining 200(43.5%) females. Most were between age 6-9 years 306(66.5%) and 77(16.7%) were 10-13 years while only 25(5.4%) were more than 14 years of age.

In most 235(51.1%) age of onset was 1 to 5 years with commonest 235(51.1%) years of onset being 2014 to 2019 and majority 93(20.2%) hailed from North Waziristan and &92(20%) from Khyber Agency. Most 456(99.1%) cases were living at their homes with support of unpaid partner, family and friends and had received primary school education 435(94.6%). Most 448(97.4%) felt their health was not poor, however they felt they had disability 458(99.6%). As regards type of disability majority 211(45.9%) had right (Rt) lower limb (LL) disability, followed by 120(26.1%) with bilateral (Bil) LL and 113(26.1%) with left (Lt) LL and Rt LL hip disability & Cervical (Cx) weakness was least common 2(0.4%) each. In majority 35(51.1%) duration of disability was 1-5 years. (Table I)

Table I: Demographic charac	cteristics of study popu	lation (n=460)
Variable	Group	Ν	%
Age of Onset	1 to 5	235	51.1
(Years)	6 to 9	139	30.2
	10 to 13	65	14.1
	>14	21	4.6
Year of Onset	2003-2007	36	7.8
	2008-2013	189	41.1
	2014-2019	235	51.1
Marital Status	single	460	100
Origin	Khyber agency	92	20
	Peshawar	81	17.6
	Bannu	27	5.9
	Kohat	7	1.5
	North wazirastan	93	20.2
	Charsada	12	2.6
	Fata	9	2
	Nowshera	8	1.7
	Lucky marwat	13	2.8
	Mardan	18	3.9
	Swat	32	7
	Mohmand	6	1.3
	agency		
	Bajur	5	1.1
	Sawabi	6	1.3
	South waziristan	25	5.4
	Bunir	6	1.3
	Tank	8	1.7
	Toraghr	3	0.7

		1	0.2
	Orakzai agency	2	0.2
	Hangu	2	
	Haripur		0.4
	Shangla	1	0.2
	Di khan	1	0.2
	Afghani	2	0.4
Living circumstances &	Living at home	456	99.1
support	with support from		
	unpaid partner,		
	family, friends.	4	0.0
	living at home	4	0.9
	with support of		
F 1 (1	paid careers	0	4.0
Education	Nil	6	1.3
	Special School	15	3.3
	Primary School	435	94.6
	Secondary	4	0.9
	school		
Poor Health	Yes	12	2.6
	No	448	97.4
Do you have a disability	Yes	458	99.6
	No	2	0.4
Type of Disability	PPP-RT-LL	211	45.9
	PPP-LT-LL	113	24.6
	PPP-Bil-LL	120	26.1
	PPP-LT-UL	4	0.9
	PPP-RT-UL	4	0.9
	PPP-Rt- LL-Hip	2	0.4
	Dis		
	PPP (Bil) LL (left	4	0.9
	disc and Rt sub)		
	Cervical	2	0.4
	weakness		
Duration of disability	1 to 5	235	51.1
-	6 to 9	139	30.2
	10 to 13	65	14.1
	>14	21	4.6

Sample revealed highest WHO QOL BREF and Full tool mean score (13.11 ± 2.19 & 56.85 ± 13.43 respectively) for psychological domain and lowest (10.67 ± 2.14 & 41.81 ± 13.34) for social domain (table II).

Table II: Domain wise descriptive statistics of WHO QOL BREF & FULL tool (N=460)					
Descriptive Statistics	Brief	Full			
Domain	Mean±SD	Mean±SD			
Physical	12.74±2.78	55.07±16.85			
Psychological	13.11±2.19	56.85±13.43			
Social	10.67±2.14	41.81±13.34			
Environmental	12.31±2.06	53.03±13.08			

As regards disability, t-test statistics did not reveal significant difference for participants views regarding presence or absence of disability with P>0.5, however scores were higher for those who said there was no disability. Similarly for living with support of unpaid or paid careers no significant difference was observed with P>0.05 with higher scores for physical, social and psychological domains in those with paid careers

and higher scores for environmental domain for those with unpaid careers (table III).

Table III. That statistics for nonfigurants views recording

statistics for	participants viev	vs regarding						
disability Presence of Disability(Participant View)								
Yes (458)	No(2)	T, p-value						
Mean±SD	Mean±SD							
55.03±16.84	62.50±26.16	625,.532						
56.80±13.34	69.00±35.36	-1.282,.200						
41.78±13.35	50.00±8.49	870,.385						
53.02±13.06	53.50±21.92	051,.959						
At home with	At home with							
unpaid careers (n=456)	paid careers (n=4)							
55.03±16.81	59.50±23.69	.279,.598						
56.85±13.43	57.75±16.26	.018,.894						
41.77±13.38	47.00±6.00	.610,.435						
53.04±13.10	51.75±11.84	.038,.845						
	bility(Participant) Yes (458) Mean±SD 55.03±16.84 56.80±13.34 41.78±13.35 53.02±13.06 At home with unpaid careers (n=456) 55.03±16.81 56.85±13.43 41.77±13.38	Yes (458) No(2) Mean±SD Mean±SD 55.03±16.84 62.50±26.16 56.80±13.34 69.00±35.36 41.78±13.35 50.00±8.49 53.02±13.06 53.50±21.92 Mean±SD Mean±SD 53.02±13.06 53.50±21.92 Mean±650 Mean±650 Mean±650 Mean±650 Mean±650 Mean±650 Mean±650 Mean±650 Mean±650 Mean±6.81 S9.50±23.69 S6.85±13.43 S7.75±16.26 41.77±13.38						

Social41.77±13.3847.00±6.00.610,.435Environmental53.04±13.1051.75±11.84.038,.845Age of participant did not reveal any significantassociation (P>0.05) for all the domains, similarly age of onsetand duration of disability did not reveal any significantassociation (p>0.05) for psychological, social andenvironmental domains, however physical domain revealedsignificant association (p=0.026) with higher scores for those >14 years age of onset/ duration (table IV)

Current study did not reveal any significant association with disability type (P>0.05). Similarly no significant association was noted with education (P=0.05). However significant association was noted with income for the domains of Physical (p=0.003), psychological (p<0.001)) and environmental (p<0.001)) domains with no association with social domain (Table V)

Significant association was noted with occupation (p<0.05),

visible disability (p<0.001) and disability affecting life (p<0.001) (Table IV)

Discussion

Poliomyelitis is a disabling life-long illness which causes a multitude of deficiencies which can worsen with age and impact an individual to carryout various movements and a variety of other aspects concerning the quality of life.

Current study involving post-polio children up to 15 years of age with more than 99% having disabilities, revealed that respondents QoL as measured by WHO QOL scores in different domain areas was moderate. Whereas a study by Gocheva at University of Basel reported enhanced HRQOL in participants as regards social interactions and environmental health compared to general population, however the physical and psychological health domains were not significantly different compared to general population, however at 6 months the HRQOL scores for psychological health were significantly lowered.¹³ While Gocheva V et al. reported reduced psychological health with no significant changes in activities of daily living, 6-minute walking distance and measure of motor function during initial six months of post-polio syndrome.¹⁴

In the current study physical health illustrated lower scores (12.74 \pm 2.78/ 55.07 \pm 16.85) with inability to fulfill the needs of occupation. Similarly, Ganesh & Mishra in their study involving paraplegic cases reported that the physical domain scores were closest (49.76 \pm 18.74) and were also low in the psychological, social relations and environmental domains of QoL and there was positive correlation of physical activities' domain with all domains of QOL.¹⁵ Similarly a Turkish study by Garip Y et al. reported PPS cases had significantly increased fatigue and

Table IV: Quality of life domains versus Age, Age of onset & Duration of disability. Cross Tabulation. ANC	OVA Statistics (N=460)
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		AGE			P-Value
	1 to 5(52)	6 to 9(306)	10 to 13(77)	<u>></u> 14(25)	
Domain	Mean±SD	Mean±SD	Mean±SD	Mean±SD	
Physical	54.06±17.03	54.43±15.51	55.82±19.24	62.56±22.74	.126
Psychological	56.35±13.63	56.50±11.37	57.51±17.89	60.28±19.59	.554
Social	44.37±10.85	41.73±13.25	41.84±13.62	37.36±17.37	.195
Environmental	52.37±13.01	52.84±12.76	53.69±13.74	54.68±15.45	.852
		AGE OF ON	SET		
	1 to 5(235)	6 to 9(139)	10 to 13(65)	<u>></u> 14(21)	
Physical	53.00±15.54	57.04±15.86	56.08±20.10	62.00±23.12	.026
Psychological	55.61±11.71	58.00±12.20	57.63±18.49	60.76±19.28	.171
Social	42.77±11.58	40.94±15.31	40.14±14.19	42.05±15.10	.421
Environmental	51.54±12.30	55.22±13.52	53.00±13.28	55.24±16.23	.056
		DURATION OF DI	SABILITY		
	1-5(235)	6-9(139)	10-13(65)	<u>></u> 14(21)	
Physical	53.00±15.54	57.04±15.86	56.08±20.10	62.00±23.12	.026
Psychological	55.61±11.71	58.00±12.20	57.63±18.49	60.76±19.28	.171
Social	42.77±11.58	40.94±15.31	40.14±14.19	42.05±15.10	.421
Environmental	51.54±12.30	55.22±13.52	53.00±13.28	55.24±16.23	.056

Table V: Quality	of life domains v	versus disability	type, educatio	on and inco	me Cro	ss tabulation	. ANOVA Stat	istics (N=460)		
DISABILITY TYP	E							· · ·		
	PPP-RT-LL (211)	PPP-LT- LL(113)	PPP-Bil- LL(120)	PPP-L UL(4)		PPP-RT- UL(4)	PPP-RT-LL- Hip Dis(2)	PPP-Bil- LL(Left Disc :& Rt Sub)(4)	Cervical Weakness(2)	
Domain					Mean±	ESD				P-
										value
Physical	55.09±16.06	57.05±18.32	53.33±17.02	59.75±2	20.85	53.25±18.50	50.00±8.49	55.00±12.94	44.00±0.00	.755
Psychological	56.89±12.24	58.26±14.81	55.33±14.16	62.50±1	15.24	59.50±19.00	59.50±4.95	53.50±10.97	53.00±4.24	.766
Social	42.15±12.90	41.74±12.65	41.33±14.32	47.00±6	6.00	36.00±24.66	44.00±0.00	39.00±26.61	44.00±0.00	.964
Environmental	52.91±12.42	54.11±13.18	52.06±14.07	55.00±1	12.94	56.50±21.19	47.00±4.24	59.50±12.97	44.00±0.00	.762
		EDU	CATION					INCOME		
	Nil(6)	Special School (15)	Primary School (435)	Seconda ry/ High school (4)		Well above average(3)	Slightly above average(2 1)	Average (427)	Slightly below average(9)	
Physical	67.83±9.09	58.13±16.80	54.74± 16.80	59.50± 27.15	1.464 ,.224		62.10± 19.62	54.47±16.61	56.56±11.51	.003
Psychological	60.33±12.27	59.33±13.76	56.70± 13.34	59.25± 25.99	.365, 778	. 88.00± 0.00	62.48± 22.85	56.31±12.56	59.33±13.10	.000
Social	43.67±21.59	48.00±5.40	41.55± 13.35	43.75± 17.44	1.198 ,.310		40.81± 17.41	41.75±13.08	42.44±16.46	.316
Environmental	61.33±15.41	57.80±12.31	52.70± 13.04	57.75± 11.84	1.745 ,.157	5 83.33± 4.04	59.71± 14.78	52.35±12.70	59.33±11.96	.000

Table VI: Quality of life domains versus occupation, visibility of disability, disability affecting life cross tabulation. ANOVA Statistics (N=460)

OCCUPATION							
	Paid (1)	Voluntary	Unemployed	Education	Day	None(40)	
		(1)	(9)	(408)	Hospital/		
					center(1)		
Domain			Mear	i±SD			P-value
Physical	81.00±.	44.00±.	49.56±8.57	53.78±16.41	88.00±.	68.23±16.34	.000
Psychological	81.00±.	56.00±.	55.67±9.66	56.02±13.15	81.00±.	64.48±14.23	.001
Social	56.00±.	44.00±.	45.33±2.65	41.07±13.52	56.00±.	47.80±11.43	.031
Environmental	81.00±.	44.00±.	51.00±11.06	51.48±11.93	56.00±.	68.75±14.17	.000
VISIBLE DISABIL	.ITY						
	No(26)	Little (36)	Moderately (23)	Mostly (372)		Totally (3)	
Physical	88.54±4.84	75.14±7.22	59.78±9.07	50.80±13.81		17.00±6.93	.000
Psychological	84.81±5.85	70.42±8.01	59.96±6.65	53.77±10.57		10.67±9.71	.000
Social	51.04±13.00	46.28±7.83	46.52±11.49	40.66±13.35		14.67±7.51	.000
Environmental	69.00±10.15	63.25±11.57	61.61±11.95	50.63±11.73		23.00±6.93	.000
DISABILITY AFFE	ECTING LIFE						
	Hardly(28)	Mildly(44)	Moderately(365)	Severely(19)		Profoundly(4)	
Physical	88.00±5.06	70.18±15.44	51.33±13.33	50.53±14.50		20.50±9.00	.000
Psychological	84.32±5.96	67.16±12.63	54.29±9.64	50.68±16.09		14.25±10.69	.000
Social	51.39±12.58	45.00±9.31	41.37±12.87	34.32±18.90		15.75±6.50	.000
Environmental	70.11±10.62	61.02±13.35	50.83±11.58	56.05±13.41		31.25±17.44	.000

reduction in QoL as regards mobility, energy and pain compared with those who did not have PPS while functions of social, emotional and sleep were not different ¹⁶. Though cases with post-polio face increasing physical disability, however these cases with late effects of disease are physically active, however most of this is in form of activities of daily living (ADL) in home and not the traditional exercise.¹⁷

In contrast to physical function, in relation to mental function Jacob & Shapira in their study involving 101 post-polio cases reported normal mental function, this being in agreement to results of the current study ⁹. While, a study by et Sayyar S et

al. reported significant (p=0.02) difference as regards physical health and no significant difference as regards mental health between post-polio athletes and non-athletes ¹⁸. Literature reveals that social brace is equally essential and plays its role in mental wellbeing of those affected with disability, hence professionals should ensure development of quality relationships of disabled with peers.¹⁹

Literature reveals that cases with diminished physical functioning might have normal mental scores in QoL because of previous coping techniques.¹⁹ This is quite evident from current study in which the psychological domain scores are higher than the mean physical domain scores for all disability types.

Shing SLH et al reported that though motor loss is a major loss, however PPS affects like due to non motor issues too including fatigue.²⁰ In the current study also PPS moderately affected life in majority of cases.

Following polio, the PPS with its disabling potential can affect life 15 to 40 years later.²¹ However in the current study the physical, psychological and environmental domain scores were higher in cases with duration of disability of more than 14 years, however the difference was not significant.

Current study also revealed significantly lower mean scores for the domains of Physical, psychological, social and environmental with the visibility of disability compared to no or less visible disability. Also QoL is significantly affected when the disability is affecting life, with very low QoL domain scores for those in which disability is severely and profoundly affecting life. Similarly literature supports this notion and hence it was reported by Selander H et al. that using a car increases the individual's mobility and chances of employment hence increase the QoL while public transportation restricts the same ²². In one study 58.5% cases with old polio were on job and using assistive devices to improve mobility and dependency for activities of daily living affected employment.23 Literature reveals that PPS is associated with fatigue, problems with sleep, reduced endurance, pain, sensory symptoms, neuropsychological defects in addition to motor functional issues, affecting QoL.24

Though no significant association of age with QoL was noted, however, according to Winberg C et al, there is association between physical activity of these cases with life satisfaction and age, hence activity is an essential factor for satisfaction among elderly.¹⁷ Another study reported significant correlation of age of onset of first polio attack and physical health (r=0.69) and fatigue (r=0.59) but no sig correlation with mental health (r=0.09) and pain (r=0.24).¹⁹ Similarly in current study significantly higher physical domain scores were noted in those with first attack more than 14 years back, while there was no significant association for psychological, social and environmental domain scores.

In current study no significant association of quality of life domains was noted with education. Similarly a study by Farbu E et al. revealed that polio did not lower the status of patient's education.²⁵

Current study revealed significant association of physical, psychological and environmental domains of QoL with income with higher scores for those with above average income, while all domains of QoL revealed significant association with occupation with higher scores for those in paid jobs. However the irony of the disease is such that according to Farbu E et al. at 40 years of age, significantly lesser number of post-polio cases were able to get full time job compared to their siblings especially the patients with paralysis.²⁵

In another Pakistani study by Lodhi FS et al. involving general population, advancing age, low socioeconomic status, living in rural setup predicted poor QoL in all domains.²⁶

Limitations: Since study was conducted in only in one province of Pakistan, its results cannot be generalized.

Conclusion

The quality of life of post-polio cases disabilities in KPK & KPTD is compromised with highest domain score for psychological followed by physical and environmental domains, the least score was of social domain. Quality of life revealed significant association occupation, visibility of disability, disability affecting life; and its physical domain with Age of onset & duration; physical, psychological and environmental domain with income.

COI: The authors report no conflict of interest.

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