



Original Article

## Enhancing Knowledge of Family Caregivers and Quality of Life of Patients with Ischemic Stroke: A Quasi-Experimental Study

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### ABSTRACT

**Objectives:** A Quasi-Experimental study was conducted to determine the impact of Attend-trial-based interventions on the knowledge of the caregivers and the quality of life of Ischemic stroke survivors.

**Material and Methods:** The study was conducted in the acute care hospital located in the rural area, Khyber Pukhtoonkha. A sample of 115 patients and informal caregivers participated in a multifaceted intervention including educational sessions, training and demonstration, and post-training discussion via WhatsApp. A pre-post evaluation of the quality of life, stroke knowledge, functioning, and activities of daily living was completed using validated tools. All information was collected using predesign pro forma and questionnaire.

**Results:** The interventions significantly improved all four outcomes in caregivers and patients. The mean score for the WHOQOL-BREF pre-intervention was  $2.91 \pm 1.10$  which was increased to  $4.18 \pm 0.86$ . The pre-knowledge scores were 34.00 which increased to 39.95. There was a statistically significant change between pre and post knowledge scores [ $t(114) = -3.394, p = 0.001$ ].

**Conclusion:** The study contributed towards the usefulness of multifaceted education intervention to enhance the rehabilitation efforts of patients and their caregivers in community settings.

**Keywords:** Stroke; informal caregivers; quality of life; home care; community care; experimental.

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### INTRODUCTION

Globally, stroke is the second leading cause of death and disability. According to the Global Burden of Diseases (GDB)(2019), the newly diagnosed cases of stroke were 12.2 million, whereas the number of existing cases was 101 million.<sup>1</sup> Simultaneously, disability-adjusted life years (DALY'S) after stroke were 143 million, 6.55 million death occurred due to stroke.<sup>2</sup> According to the recent United Nations estimates, South Asia's population is equivalent to 24.89% of the

total world population.<sup>3</sup> A survey was conducted in China with 480687 participants; significantly (7672) were identified as stroke prevalence (1596/100000) people and 1643 as stroke incidence (345.1/100000) persons per year.<sup>4</sup> Pakistan is a country in South Asia and the world's fifth-most populous country, with about 226 million<sup>5</sup>. The correct incidence and prevalence of ischemic and hemorrhagic stroke are not yet validated. In the aging population, stroke incidence is very high compared to young adults in Pakistan, which is approximately 11%. A rough estimation was made to be 19000 per 100,000.<sup>6</sup> Population and community – based studies from developed countries have shown that incidences and prevalence of stroke can be lessened through different treatment modalities. However, the existing literature shows that no intervention-based studies have been tested in the low-resource settings of developing countries such as Pakistan,<sup>7</sup> which clearly shows the gap for research in the global and Pakistani contexts. This study reports the findings of an interventional study to enhance the knowledge and quality of life of patients and their caregivers.

The impact of stroke on the quality of life of both stroke patients and their family caretakers is well-noted. Increased symptoms of depression that continue for years after stroke have been observed higher than matched non-care giving family members.<sup>8</sup> While caring for the stroke survivors, the quality of life; social well-being, emotional and psychological status can also be affected for “Not only” of patients but also of family members and others who play a significant role in creating an effective environment.<sup>9</sup> They strive to encourage their patients physically and give them psychosocial support. About 80% of the ischemic stroke patients are discharged from the hospital, and they are cared for by their spouse, son, daughter, and other family members. During the care, they often face challenges related to the care, exercises, assistance, and proper guidance for the activities of daily living.<sup>10</sup>

Hence, these complex challenges can result in a decline of the caregivers' and their patient's health status, social life, and well-being.

Caregivers of patients with stroke experience a great amount of burden. Previous studies particularly the cross-sectional studies, revealed that due to the lack of stroke knowledge, an increased burden is experienced in 51% of the close family members one year after stroke.<sup>11,12</sup> Highlighted that a comprehensive educational program could greatly enhance stroke caregivers' knowledge, reduce the burden of stroke, and, more importantly, reduce the pre-hospital delay due to the lack of Ischemic stroke knowledge. Similarly, a local area-based program for family caregivers for after-stroke survivors in Thailand identified that the required skills of family caregivers for stroke were significantly improved after the intervention. After training, the functional status of the ischemic stroke survivors and decreased their complications.<sup>13,14</sup> did a systematic review and found that the pragmatic solution to stroke recovery and improved quality of life in low-and middle – income countries is to have low – cost rehabilitation techniques demonstrated to the caregivers of the patients. Given the importance of improving caregivers' knowledge and the greater need to improve the quality of life of caregivers and patients, this study was conducted to test an educational intervention. The present study was conducted to evaluate the effectiveness of ATTEND TRAIL-based Intervention to enhance the knowledge of informal caregivers of patients suffering from ischemic stroke and improve the quality of life of patients in low – resource settings.

## **MATERIALS AND METHODS**

### **STUDY DESIGN, SETTING, AND SAMPLING**

A quasi-experimental study approach (One – group pre and post-test) was used for this study.

This design was best suited to assess the baseline knowledge of the stroke caregivers and the quality of life of ischemic stroke patients. The study was conducted in the acute care hospital located in the rural area, Khyber Pukhtoonkha from June 2021 to December 2021. Patients, as well as their caregivers, were recruited conveniently from an acute care hospital located in Peshawar, Pakistan. Afterward, an informed consent form was completed by the participants. At the same time, study purpose, objectives, risks, and benefits were also explained to the patients and their caregivers. The patients had their informal family caregivers, and they were also willing to learn rehabilitation techniques to make better the quality of life of their patients.

Considering the level of significance = 5%, and power = 90% the following formula of calculating sample size is used:

$$n = \frac{(Z_{\alpha/2} + Z_{\beta})^2 \times 2\sigma^2}{d^2}$$

Where n = sample size, d = significant difference (effect size)/ margin of error.

$\sigma$  = standard deviation,  $Z_{\alpha/2}$ : Normal Z value for the level of significance and  $Z_{\beta}$  is the normal value for the power.

Given the above equation, the sample size required 115. A distribution ratio of 1: 1 was selected to increase power to detect statistically significant variances between the four groups.

## Sampling Criteria

The inclusion criteria for the patients were as follows: a) have stroke disability that required help from others b) with a pre-determined primary informal caregiver bigger than 18 years c) No established disability before the stroke, which was determined and defined by (Modified Rankin scale = 0) d) Living in the district Peshawar.

In the same manner, the investigators defined different inclusion criteria for caregivers such as a) permanently living with the patient or at least for six months b) should not be a health care

provider; c) willing and consent to include in study d) provide unpaid care. This sample was estimated using the observed difference reported by Kalra et al. (2004) between the caregivers' burden after an intervention.

## Data Collection Procedure

The researchers included an expert physiotherapist to accurately demonstrate the exercises and train the family caregivers for this study. In the first phase, the researchers collected pre-data from both the participants, and then the researcher visited each patient's home. Those patients and their caregivers who were able to come to learn the interventions were encouraged. Moreover, interventions were delivered in a group shape in a commonplace in the community called HUIRA. For demonstration, researchers have used multimedia to show them exercises, and pamphlets containing all exercises were also distributed. In addition, caregivers who had smartphones have been added to a WhatsApp group in which they could ask any question regarding the exercises.

These interventions included activities of daily living, movement exercises, a basic form of evidence – based rehabilitation therapy, and include information provision, specific task activities. These training sessions were for one hour a day. After the sessions, the researchers made random visits to the patient's home to assess the continuity of the caregivers' training to their patients. They were again encouraged to call the researcher if they had any difficulty in performing the training. The interventions continued for 12 weeks. The intervention was designed so it could be delivered by a physiotherapist and the researcher (Nurse). A physiotherapist led the intervention training. Initially, the caregivers and patients were recruited; the neurosurgeon had already diagnosed them. The patients and their caregivers were strongly encouraged to maintain their daily progress log of exercises for 2 – 3 months.

## Data Collection Instruments

After that, before intervention for patients who had an ischemic stroke, their comprehensive assessment of disability and impairment was measured by different tools such as Modified Rankin Scale (MRS), Barthel Index (BI), and their scorings are following:

MRS was used to assess functioning.<sup>15</sup> It comprises seven levels. Patients who had scored from 0 – 2 mean good scores and independence in care. Similarly, from 3 to 5 score means that the patient is having an increased level of disability, and lastly, six score means death. The general and basic activities of daily living (ADL) were measured by the Barthel index.<sup>15</sup> To further explore it, it comprises 10 scales which include feeding, grooming, dressing, bladder management, toilet use, bathing, bowel management, mobility, and stairs. We calculated patients' scores for individual items, and the total possible score ranged from 0 – 20. If the patient had lower scoring, it indicated (totally dependent) whereas the maximum possible score for this tool is 100, which indicates (independent). These two MRS and Barthel indexes are largely used in different stroke studies.

The Stroke knowledge test (SKT) was used to assess caregivers' knowledge regarding stroke.<sup>16</sup> Before using this tool, permission was granted by the developer. This tool was actually in English, but it was then used for patients after pilot testing and back to forward translation in Urdu. It comprises 20 multiple – choice questions. Each question had five multiple choices. Out of five, One was correct and one "I do not know" the rest three were used as distractors. After the data were obtained from caregivers, each correct answer was marked 1, and if the answer was wrong, it was given a (0) mark. Overall score calculation for SKT was 0 – 30% was considered poor knowledge, 31 – 60% was considered average knowledge; 61-100% was considered Good knowledge.

The WHOQOL-BREF self-administered tool in

Urdu (Pakistani version) was used. The Psychometric properties of this version were determined by.<sup>17</sup> They calculated the internal reliability of the Urdu version, which was 0.86. This tool covers 26 questions in all four domains (physical health, psychological/mental health, social relationship, and environment) and generally Quality of life. There are six things for the psychological/mental domain (negative thinking, self-perception and appearance, constructive feeling, self-esteem, approach, ability to learn, remembrance and attentiveness, consolidation, religion, and cognitive condition), seven items for the physical domain (mobility, daily life activities, pain and discomfort, sleep and rest, functional capacity, and energy and fatigue), 3 for the social domain (personal relationship, sexual relationship, social support), and eight for the environmental domain (financial resources, security and freedom, well – being and community services, living in natural environment, freedom to achieve advance learning, relaxation, and natural environment like free of air contamination, and safe transportation). For each question, five categories ranged from (1 – 5). By the user manual of WHOQOL-BREF, raw scores were converted into the transformed score using a Table to show what is considered the final score in that particular domain. As no cut-points existed to classify the QoL measured by WHOQOL – BREF, the final score ranges from 0 to 100. The total scores demonstrate the level of QoL; lesser scores show a lower QoL while greater scores show a higher QoL.<sup>18</sup>

## Ethical Considerations

The ethical approval for the study was obtained from the relevant ethics committee (Reference # IRB-UOL-FAHS/857/2021). The rights of the participants were regarded with respect. Initially, Informed consent was taken from all the study participants. All information regarding the participants and data collection was confidential kept. Furthermore, Participants have remained

unidentified during the study. They were further educated that they will be allowed to leave or stop at any time throughout the study.

## RESULTS

### Demographics

Of 115, there were male caregivers (67.83%) than the female (32.17%), with a majority of caregivers aged 18 – 40 (66.96%), followed by 40 – 50 years (26.96%). Most of the caregivers identified as “Son” of the stroke survivors (33.04%), followed by brother (21.74%). The High school students were more active in caregiving to the stroke

patients than primary, college, and university level students. Concerning occupation, the majority of the caregivers were students (34.78%), while the lowest percentage was recorded for others (Driver, labor, and watchman) (3.48%). In terms of patients, the percentage of male patients (59.13%) was higher than the percentage of female patients (40.87%). The majority of patients were aged 18 – 40 (29.57%) followed by 60 – 70 (20.0%). A large number of patients were married (99.13%). Similarly, the illiterate and below primary patients were equal and higher in percentage with 27.83 than other education levels (Table 1).

**Table 1:** Demographics.

Caregiver Characteristics		N	%	Patient Characteristics		N	%	
Gender	Male	78	67.83	Gender	Male	68	59.13	
	Female	37	32.17		Female	47	40.87	
Age	18 – 40	77	66.96	Age	18-40	10	8.70	
	40 – 50	31	26.96		40-50	30	26.09	
	50 – 60	5	4.35		50-60	35	30.43	
	60 – 70	2	1.74		60-70	25	21.74	
	Husband	2	1.74		Marital Status	Married	114	99.13
Mother	7	6.09	Unmarried	1		0.87		
Father	10	8.70	Illiterate	32		27.83		
Caregiver	Wife	10	8.70	Education	Below primary	32	27.83	
	Brother	25	21.74		Primary	22	19.13	
	Sister	21	18.26		High School	16	13.91	
	Son	38	33.04		High secondary school	9	7.83	
	Daughter	2	1.74		College	3	2.61	
Education	Primary	30	26.09	Occupation	Teacher	5	4.35	
	High school	36	31.30		Army	3	0.00	
	College	26	22.61		Plumber	11	9.57	
	University	23	20.00		Former	52	45.22	
	Teacher	13	11.30		Shopkeeper/businessman/landlord	46	40.00	
Occupation	Plumber	7	6.09	Property	Retired	1	0.87	
	Former	20	17.39		Owner	73	63.48	
	Students	40	34.78		Tenant	42	36.52	
	Housewife	17	14.78		Medical History	Diabetes mellitus	23	20.00
	Shopkeeper	14	12.17			Hypertension	62	53.91
Others *	04	3.48	Smoker	2		1.74		
Stroke related Complications during hospitalization		Obesity	8	6.96				
		Dyslipidaemia	2	1.74				
		Pressure ulcer	8	6.96				
		Incontinence	7	6.09				
		Dysphagia	21	18.26				
		Aphasia	40	34.78				
		Other*	5	4.35				
		No complication	34	29.57				

## EFFECT OF INTERVENTION

### Quality of Life

The mean score for the WHOQOL – BREF pre-intervention was  $2.91 \pm 1.10$  which was increased to  $4.18 \pm 0.86$ . Similarly, satisfaction from health was measured and it was increased to  $4.34 \pm 0.61$  from  $2.86 \pm 0.99$ . A significant improvement in the overall QOL of the stroke patients was observed (Table 2).

### Barthel Index

The mean score of the patients on the Barthel index before intervention was  $6.30 \pm 2.11$  which is lesser than that of the patients after intervention with  $13.64 \pm 1.71$  [t (114) = -30.68, p < 0.01 (Table 3).

### Modified Ranking Scale

The mean score of MRS before the intervention was  $3.30 \pm 1.03$  and after the intervention, the mean was  $2.09 \pm 0.79$  (p < 0.01) and the effect of intervention remained statistically significant with the paired mean difference of -1.01 to -1.48 (Table 4).

### Stroke Knowledge Test

An improvement of  $39.65 \pm 17.41$  was observed in the stroke knowledge of the caregivers post-intervention. The pre-knowledge scores were 34.00 which increased to 39.95. There was a statistically significant difference between pre and post-knowledge scores [t (114) = -3.394, p = 0.001] (Table 5).

**Table 2:** Overall Quality of Life and Health of the Ischemic Stroke Patients.

Overall QoL and Health	Mean	SD	Minimum	Maximum	P-Value
How would you rate your quality of life? <b>Pre</b>	2.91	1.10	1.00	5.00	
How would you rate your quality of life? <b>Post</b>	4.18	0.86	3.00	5.00	
How satisfied are you with your health? <b>Pre</b>	2.86	0.99	1.00	5.00	
How satisfied are you with your health? <b>Post</b>	4.34	0.61	3.00	5.00	
			<b>T-test</b>		
Domain 1: Physical Health			T-value	Df	
Pre	39.66	14.77	-15.442	114	P < 0.01*
Post	64.82	7.63			
Domain 2: Psychological Health					
Pre	43.06	19.24	-14.502	114	P < 0.01*
Post	72.31	8.85			
Domain 3: Social Relationships					
Pre	44.78	19.29	-8.921	114	P < 0.01*
Post	62.43	11.02			
Domain 4: Environmental					
Pre	45.92	16.83	-9.744	114	P < 0.01*
Post	63.55	7.33			

\*significant

**Table 3:** Pre and Post Scores of Barthel Index.

		Mean	SD	SEM	Paired t-Test			
					t-value	df	95% CI of the Difference	p-value
Barthel	Pre	6.30	2.11	0.196	-30.68	114	-7.82 to -6.87	0.000*
Index	Post	13.64	1.71	0.159				

**Table 4:** Pre and Post Scores of MRS.

		Mean	SD	SEM	t-value	df	95% CI of the Difference	p-value
MRS	Pre	3.30	1.03	0.096	10.41	114	1.01 to 1.48	0.000*
	Post	2.09	0.79	0.074				

\*significant

**Table 5:** Stroke Knowledge of the Caregivers.

		Mean	SD	SEM	t-value	df	Paired t-test 95%CI of the difference	p-value
Stroke knowledge of the caregivers	Pre	34.00	17.43	1.63	-3.394	114	-10.95 to -2.88	0.001*
	Post	39.65	17.41	2.00				

\*significant

## DISCUSSION

The study aimed to assess the impact of Attend trial-based intervention on knowledge of the stroke patient's caregivers and the quality of life of the patients with stroke. Previous literature indicated that lack of knowledge and inefficient skills of caregivers regarding the stroke was related to late recovery, financial burden, seriously affecting the quality of life of the stroke patients in low resource settings.<sup>19</sup> Furthermore, the awareness of the general public and even general healthcare practitioners about the manifestations of an impending/ growing stroke is insufficient.<sup>20</sup> This results in loss of valuable time wherein patients can report to the hospital and get urgent medical attention.

Families and caregivers of the ischemic stroke patients should be instructed and trained to direct their care in making a stroke patient stabilized and independent. The literature further highlighted that Short term and long-term rehabilitation care protocols, as well as trials, are required to be established and followed to make sure best practices.

The results of this study significantly supported the effect of ATTEND TRIAL-based interventions on the knowledge of the stroke patient's caregivers. also consistent with the previous studies. The knowledge and skills improvement of the family caregivers resulted from the application of ATTEND trail-based intervention, which included structured –

rehabilitation training, joint goal setting, and task-specific training by the researcher and an expert physiotherapist. ATTEND trial, which focuses on rehabilitation, is a randomized, open trial with a blinded endpoint. It is a unique trial among all available randomized control trials. The reason is, it is the largest trial as the AVERT trial. In addition, it is designed to address priorities set out in the World health organization (WHO)/ World Bank Report on Disability.<sup>21</sup> We used this trial because it was used in India; however, it did not decrease death or dependency; neither was an improvement observed at three and 6-month assessments in India. Pakistan and India are the same in terms of geography, food, religion, practices, and traditions in many contexts.

Several studies across the globe have shown that the conventional knowledge of stroke in the overall population is typically insufficient in both the developed<sup>22</sup> and developing nations. In a study conducted in the Arabian Gulf emirates, numerous patients and their informal caregivers were not well informed about the term 'stroke'.<sup>23</sup> Similarly, in Pakistan, study participants' from secondary schools in only one district revealed that they knew nothing about the risk factors for stroke and the basic manifestations of the stroke. In addition, they did not know what to do in an emergency of acute ischemic stroke attack.<sup>24</sup>

Our study revealed a significant stroke

knowledge improvement observed among the caregivers of the patients after the intervention, which was  $39.65 \pm 17.41$ . The finding is consistent with that of,<sup>25</sup> who used the same Quasi-experimental pre and post-design to evaluate the effectiveness of the post-stroke care program within the community setting in Thailand. They had the p-value  $< .001$ . They further highlighted that providing specific education about caring for ischemic stroke patients and during recovery after stroke resulted in improved family caregivers' awareness and a better understanding of their patient's care and rehabilitation. These findings of the current study further support existing literature<sup>26</sup> that shows education and information regarding the nature of stroke, recovery, rehabilitation, primary and secondary preventions are the critical components of skill development.

The results of this study significantly supported that there is a significant effect of ATTEND TRIAL – based interventions on the QoL status of ischemic stroke patients. In this study, we used the Barthel index (BI) which is used to assess and measure the performance in activities of daily living, and the Modified Rankin scale (MRS) to measure the degree of disability in stroke patients. The current study results show that the patients' mean score before intervention was  $6.30 \pm 2.11$  which is lesser than that of the patients after intervention with  $13.64 \pm 1.71$  and the post results for MRS are substantially better than the pre-intervention. The mean before the intervention was  $3.30 \pm 1.03$  and after the intervention, the mean was  $2.09 \pm 0.79$  the p-value was 0.00 and the effect of intervention remained statistically significant with the paired mean difference of -7.82 to -6.87. The results of the current study are supported by<sup>27</sup> who described the significant change in the BI scores from discharge till three months and after discharge by using the random intercept model among patients with acute ischemic stroke in Malaysia. In their study, they have discussed that the overall mean BI score improved to almost

83.5% (from 35.1 to 64.4) and 104% (from 35.1 to 71.5) after discharge to 1 month and from then to 3 months respectively. It further suggests that considerable recovery from acute ischemic stroke had taken place during these periods, more specifically from the time of discharge and 1 month. This initial recovery can be regarded as spontaneous neurological development. This can happen within 3 months post-ischemic stroke.<sup>28</sup> Nevertheless, within six months and two years after acute ischemic stroke and if the interventions are continued, the BI score will significantly improve.<sup>29</sup>

MRS and WHOQOL – BREF scales were additionally used to evaluate the degree of disability in the daily life activities of the ischemic stroke survivors or patients having a neurological impairment. WHOQOL-BREF is used to assess the IS patients in four domains such as physical, psychological, social, and environmental. In the current study, the researcher observed significant improvement after the intervention of 12 weeks. The mean score of MRS post-intervention is  $2.09 \pm 0.79$  from  $3.30 \pm 1.03$ . At the same time, for each domain 1 – 4 of WHOQOL – BREF, significant differences have been observed in the patient's life after intervention where the P-value is 0.000. The QoL before the intervention was poor which can be seen in our results and this is consistent with the previous study<sup>30</sup>. But after educating the patient and their caregivers the QoL improved. These findings are supported by<sup>18</sup> who studied and noticed the quality of life functional effects, social help of Ischemic stroke patients in an urban area of Thailand. They highlighted that if we give the stroke survivors functional and social support, as a result, we will have a significant improvement in the quality of life of IS patients. They<sup>18</sup> further elaborated that functional, social support significantly modified all QoL domains (covering by WHOQOL – BREIF) of patients after stroke. Additionally, if the physical outcome and social domain are improved, it will



positively affect the psychological and environmental domain of QoL.

## CONCLUSION

Assessing caregivers' knowledge and skills and improving the health status of stroke survivors is essential for health care providers. Nurses as caring agents and healthcare professionals, need to assess caregivers' knowledge and skills after discharge of the stroke patients from the hospitals or specialized care units to maintain good healthcare practices and maintain the good health of patients who are stroke survivors. Nurses are the fundamental component of the healthcare system that is directly related to patient assessment and care provision. Similarly, one of the essential roles of nurses is to educate the community as well. While dealing with complexities of neurological and pain assessment of patients in hospitals. Despite all the advances in technologies, treatments, and recognizing the pathophysiology, epidemiology, and risk factors of transmittable and non-transmittable diseases and infections, stroke remains the subsequent driving reason for death. Low-income countries, particularly in low-resource areas people are unaware of the basic knowledge regarding ischemic stroke. Due to which there is huge financial distress, the burden on the health system, and eventually upon family caregivers. Proper education regarding the disease and rehabilitation can overcome the problem.

## Limitation of the Study

A convenience sampling was used for recruitment which could have resulted in selection bias. The intervention was implemented only once and follow-up was two months. Future studies could use interrupted time series to establish the usefulness of intervention. Finally, the literacy level of family caregivers could have affected the uptake of intervention content.

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### Additional Information

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**Ethical Review Board Approval:** The study was conformed to the ethical review board requirements.

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**Conflicts of Interest:**

In compliance with the ICMJE uniform disclosure form, all authors declare the following:

**Financial Relationships:** All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work.

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### AUTHORS CONTRIBUTIONS

Sr.#	Author's Full Name	Intellectual Contribution to Paper in Terms of:
1.	Muhammad Ayaz	Paper writing, data calculations/analysis, study design, results, referencing, literature review and methodology.
2.	Mumtaz Ali khan	Data collection and calculations.
3.	Adnan Yaqoob	Analysis of data and interpretation of results etc.
4.	Hajra Sarwer	Analysis of data and quality insurer.