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Introduction

The Pakistan hemophilia patient's welfare society (PHPWS) is a dynamic voluntary, nonprofit voluntary philanthropic organization established by the people with hemophilia for the people with hemophilia. It is geared to provide professional advise, preventive, educational and medical assistance to hemophilia patients and their families..

Raising awareness through networking, advocacy and education about hemophilia related issues are the prime agenda of PHPWS.

The Rawalpindi/Islamabad chapter of the society has been collaborating with various international organizations like world federation of hemophilia (WFH) and Novo Nordisk hemophilia foundation (NNHF) to improve diagnosis, treatment and awareness standards The first NNHF project focused on education of patients and their families by developing material in local language (Urdu).Involvement of the media and Government representatives improved disease awareness at a national level. This project was extended to train Master trainers in the 4 provincial capitals in collaboration with NNHF.



PHPWS



Interactive Session

Objectives

It focused on skill development and awareness towards management issues in hemophilia by training key staff in the provincial chapters of the society so as to sustain and continue the education in their respective areas.

Strategy:

The strategy included identifying key personnel in the provincial chapters for training, developing a training module on conducting training and holding capacity building workshops to transfer knowledge & skill from the resource team to the local master trainers.



Booklet reading



Practical Demonstration

Methods

Booklet Dissemination



The project was divided into 4 quarters. Hiring of the staff, procurement of equipment and project launch were in the first quarter. Development of the training module and training kits, translation of Urdu booklets in English and development of brochures in Urdu and English took place in the 2nd quarter.

Development of the training module: The training module was developed by the project team and reviewed & edited by the technical committee members. It was pre tested in a workshop before it was printed.

Development of booklets & brochures in Urdu & English: Keeping in view the need for local awareness material the technical committee developed booklets and brochures on different aspects of hemophilia in Urdu & English.

Development of training kits: These were developed in the third quarter to supplement the training module and used for giving practical demonstration. They had all the necessary equipment to handle bleeds.

Master trainers workshops: Educational workshops were organized in all 4 provincial capitals (Peshawar, Lahore, Karachi & Quetta) Participants of the workshops included doctors (hematologists, dentists, physiotherapists, gynecologists & pediatricians), nurses, paramedics and hemophilia patients and their families and media personnel.

The format of the workshops included: Plenary session in this session the resource team was introduced along with their objective of skill & expertise transfer to the local master trainers.

Educational session this was conducted with the help of booklets by showing the participants the techniques for home/self care, joint problems and their management, physiotherapy techniques and dental care. The details & problems of females with bleeding disorders were also discussed along with the psychological pressures.

Demonstration session practical demonstrations on factor preparation, techniques of ICE treatment physiotherapy and dental techniques Media awareness electronic media personnel also participated in the workshop to create awareness about bleeding disorders. Recordings of the workshop and interviews of the organizers & resource team were also aired and printed in the local newspapers.

Knowledge, attitude & practices (KAP) survey was conducted pre & post workshop to assess the knowledge gained.



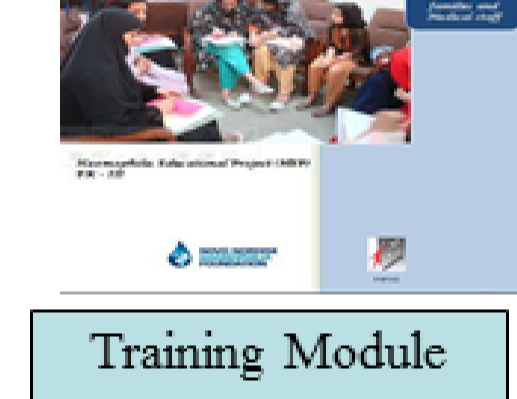
KAP Survey



Karachi Wksp



Training Kit

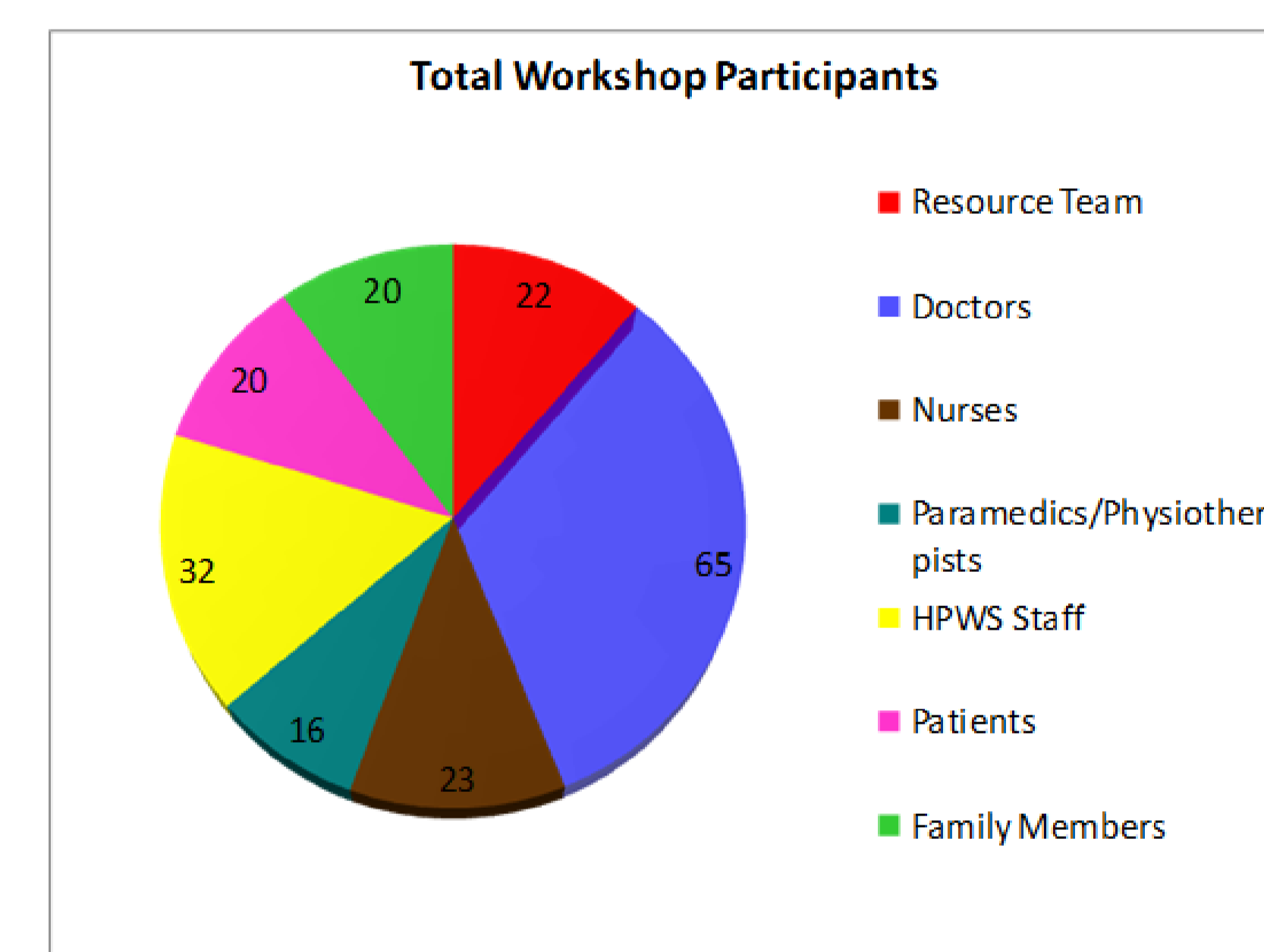


Training Module



Graphs and tables

Provincial Workshops Participants							
Participants	No	Participants	No	Participants	No	Participants	No
Resource Team	05	Resource Team	07	Resource Team	05	Resource Team	05
Doctors	08	Doctors	20	Doctors	15	Doctors	22
Nurses	08	Nurses	05	Nurses	06	Nurses	04
Para Medics	04	Paramedics	034	Paramedics/Physiotherapists	06	Paramedics	02
Staff members from HPWS Karachi	04	Staff members from Frontier Foundation	18	Staff members from HPWS Quetta	05	Staff members from HPWS, LHR	05
Patients of Haemophilia	12	Patients of Haemophilia	02	Patients of Haemophilia	03	Patients of Haemophilia	03
Family members	12	Family members	04	Family members	02	Family members	02
Total	53	Total	60	Total	42	Total	43
Karachi		Peshawar		Quetta		Lahore	



Results

198 care givers were trained .KAP survey showed improved post workshop ratings.

Peshawar Workshop: First of the series of four workshops. Total number of participants sixty, including Doctors, Nurses, Paramedics, few patients and their families.

Quetta Workshop: Held at provincial Sandman hospital Quetta. Forty two participants were trained including Doctors, Nurses, Paramedics, NGOs working in the field of health patients and their families.

Karachi Workshop: held at National Institute of Blood Diseases Karachi. Fifty three participants attended the workshop. These included Doctors, Nurses, Paramedics and Hemophilia patients and their families.

Lahore workshop: held at The Children Hospital and the Institute of Child Health Lahore. Total of Forty Three participants were trained including doctors, Nurses, Paramedics, Official from Governmental and Non Governmental Organizations and Patients of Haemophilia.

Governmental support: The involvement of government officials resulted in improved treatment of the Haemophilia patients through government support.(Pakistan Bait ul Mall, A government organization pledged treatment and financial support to two hundred haemophilia patients.)

Media Involvement: inclusion of media personal created awareness at National and international Level. Television interviews, led to increased understanding and plight of haemophilia patients with pledge of support from the civil society.



Quetta wksp



Lahore Wksp



Karachi wksp



Peshawar wksp

Conclusions

Master trainers workshops resulted in increased awareness and improved treatment skills of hemophilia management throughout the country. They were a good learning experience and were accepted as extremely important for continuing awareness and education of Hemophilia patients and their care givers through the country. This led to increased confidence of the provincial teams to sustain these activities at the local level. The government has assured support to continue these activities. Media Involvement led to national awareness and international recognition of the project activities.

References:

Education of Patients with Haemophilia and their families in Pakistan PK-II Project Report
Education of Patients with Haemophilia and their families in Pakistan PK-III Project Report

