Childhood Rickets in Cox's Bazar 2009

Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV), Bangladesh

Supported by

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Childhood Rickets in Cox's Bazar 2009

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1. Foreword

Social Assistance and Rehabilitation for Physically Vulnerable (SARPV) Bangladesh is an advocating organization in the development arena. It has been working since 1989 to develop a society where persons with disabilities can enjoy their rights and opportunities as parts of the mainstream. Working on this issue SARPV Bangladesh has been trying to see the association between rickets and disability. Rickets was first brought before public attention in 1991 by SARPV personnel after visiting Chakaria Upazila where approximately 1% children had rachitic deformities. Initial studies suggested that Vitamin D deficiency was not the major cause of rickets in Bangladesh and calcium deficiency is assumed to be the etiological factor.

Rickets is preventable and curable if identified and treated at an early stage If detected at an early stage of deformities only nutritional advice and medicine can suffice. For more than 20 degrees of leg deformity, surgery or brace is used as needed. It is more important to raise mass awareness on rickets.

As SARPV Bangladesh dreams of a “Rickets-free Bangladesh”, it has undertaken “Prevention of Rickets through Nutrition Project” under its disability prevention program, with the assistance from UNICEF, to materialize the dream. This is a pilot project with the aim of having rickets-free Cox's Bazar Sadar, Maheskhali and Chakaria Upazilas in Cox's Bazar district and increasing the use of iodized salt. The project duration is 3 years (2008 - 2010). Now the project is in its second phase.

This is the second time UNICEF has come forward to take an initiative to support the rickets prevention program through nutrition and raising awareness.

SARPV Bangladesh is trying to address the issue keeping a child-centered approach in mind. The children are the victims of this disease and if we do not take care of them at the right time, then rickets will turn it into disability.

Notable activities of the project include identifying ricketic signs among children below 5 years, educating mothers of rickets-affected children to form groups, encouraging to have calcium-rich vegetable, cooking rice with lime (chun) @1 mg chun in 1 kilo rice, and providing physiotherapy and assistive device.

The project is the result of help and co-operation of many. We would be failing our duties if their cooperation and valuable contributions are not mentioned and acknowledged.

First of all, the contributioin of the children with Rickets and their families who accepted our nutritional intervention with a positive attitude deserve to be acknowledged.

Thanks are also due to the project team who diligently worked in the project areas and my colleagues at the head office of SARPV for their co-ordination and interaction with the donor, project team and the partners of SARPV, Media and all other stakeholders.

The officials of the government, NGOs and DPOs deserve appreciation and thanks for becoming sensitized on the issue of Rickets and being supportive to our activities to that end.

Last but not the least, UNICEF Bangladesh deserves special appreciation not only for taking active interest and enthusiastically coming forward to support the initiative to prevent rickets and to reduce the disability from the society, but also for extending guidance and moral support from time to time.

SARPV remains deeply appreciative of its members, funders, volunteers, and partners for their supports, without whom it would be, no doubt, absolutely impossible for SARPV to come upto this level.

Md. Shahidul Haque
Chief Executive
SARPV Bangladesh

2. Abbreviations & Acronyms

AEM	Ami des Enfants du Monde (AEM), France (Friends of the Children of the World)
AMD	Aide Medicale et Developpement, France (Medical and Development Aid)
BMA	Bangladesh Medical Association
CBBSH	Cox's Bazar Baitush Sharaf Hospital
CIMMYT	Centro Internacional de Mejoramiento de Maíz y Trigo (International Maize and Wheat Improvement Center)
CRG	Convergence Rickets Group
DPO	Disable Person's Organization
FGD	Focus group discussion
HKI	Helen Keller International
ICMH	Institute of Child and Maternal Health
KDM	Kinesitherapeute du Monde, France (Physiotherapists of the World)
MCH	Memorial Christian Hospital
NGO	Non Government Organization
NNP	National Nutrition Project
SARPV	Social Assistance and Rehabilitation for the Physically Vulnerable
USAID	United States Agency for International Development

3. Chronology of Rickets in Bangladesh

1991 : **I**dentification of a high prevalence of rickets in the children of Chakaria in Cox's Bazar district by Md. Shahidul Haque, Founder Secy, SARPV after the devastating cyclone.

1991-1993 : **S**ARPV raised campaigns through Newspapers, Dialogue forum, Letter correspondences, Annual reports and Workshops

SARPV treated 25 rachitic children at MCH

1993-1997 : **N**utritional survey on clinical and pathological examination of rachitic children by Ami des Enfants du Monde (AEM), France

Rapid prevalence-assessment by ICMH, UNICEF and SARPV.

1994 : **D**iagnosed as calcium deficiency rickets by Dr Cimma of AEM, France

1995 : **S**upplementation trial using different Calcium & Vitamin D doses by AEM (Dr J.P. Cimma)

1997 : **T**wo Bangladeshi boys were operated in France (AEM)

Formation of a Consortium on rickets in Chakaria, Bangladesh by SARPV, Cornell University, BRAC, ICDDRB, AEM, MCH, UNICEF, and ICMH

1998 : **C**onfirmation by the consortium - the rickets in Bangladesh is a Calcium deficient form.

Rachitic children clinically and pathologically examined by Cornell University, University of Dhaka, SARPV and MCH

Supplementation trial of Calcium on 2-5 years old children by Cornell University, CIMMYT and SARPV

Household Study on Food habit of the inhabitants of Cox's Bazar and Dinajpur districts by Cornell University

1999: **P**rodipaloy (an integrated school) was set up to supervise control children under rickets research by AEM, France

Physiotherapy training started for community level physiotherapists by KDM, France

2000: **R**apid Assessment on Rickets by BRAC and HKI under Rickets Consortium

2001 : **T**raining of Bangladeshi physiotherapists started with 4 trainees by KDM in collaboration with SARPV and AMD.

2001-2003: **S**tudy on the role of Aluminium dishes on rickets by Shahidul Association.

2002 : **S**urgery begins at Cox's Bazar Baitush Sharaf Hospital (CBBSH) in collaboration with AMD, KDM, SARPV.

2003: **B**race center at Chakaria with support from AMD, France

200 children given nutritional treatment under close supervision

2004: **C**RG (Convergence Rickets Group) formed under the leadership of Dr. Craviari Thierry for concentrating and involving more expertise on rickets and sharing experiences.

2005: **O**peration of 128 Rickets children in Bangladesh initiated by SARPV with the help from AMD, France and KDM, France under the supervision of Dr. Craviari Thierry

2006: **I**nternational Rickets Conference held at Dhaka, Bangladesh organized by SARPV with participation from USA, Nigeria, South Africa and France inaugurated by the French Ambassador to Bangladesh and the President of BMA.

2007: **R**ickets Interest Group (RIG) formed as a follow up of International Rickets Conference

Dr. Thierry proposes formation of Bangladesh Rickets Society.

2008: **P**revention of the Rickets program undertaken at Cox's Bazar district with the assistance from UNICEF.

National Prevalence Study on Rickets by ICDDR,B with supports from SARPV, CARE, UNICEF and NNP

National Consultation on Childhood Rickets in Bangladesh organized by SARPV Bangladesh and RIG with supports from UNICEF.

4. Brief on Rickets in Bangladesh

PREVALENCE OF RICKETS IN BANGLADESH

Focus groups and local informants suggested that rickets was 'new' and had not been seen before the early 1970s. In 1991 SARVP brought national attention about the prevalence of Rickets in Chakaria under Cox's Bazar district. In 1994, a group of French physicians evaluated patients in communities from Chittagong to Moheshkhali and identified rickets in 4.5% of total children under 15 years old. Later it was revealed by experts that rickets was more common than suspected and it was not generally associated with vitamin D deficiency but related to dietary insufficiency of calcium.

The Institute of Child and Mother Health (ICMH) found in a survey in Chittagong division in 1998 that 8.7% of children had at least one clinical finding indicative of rickets; 4% had lower limb deformities suggestive of Rickets; 0.9% had radiological evidence of active rickets; and 2.2% had elevated serum alkaline phosphates levels.

Helen Keller International (HKI) found the highest prevalence (1.4%) of visible rachitic deformities in 1-15 year old children in the Cox's Bazar upazila in a nationwide survey in 2004.

SARPV found rickets in 0.9% of the total population surveyed in 2006 in Chakaria upazila. Interestingly, rickets has not been identified among the indigenous population living in the Chittagong Hill Tracts.

The National Rickets Survey in Bangladesh, done in 2008, was the largest initiation to screen, diagnose, and estimate the prevalence of childhood rickets in Bangladesh. A preliminary study observed that all rickets in Bangladesh may not be due to Vitamin D deficiency, and that calcium metabolism was an important cause, which may be much easier to prevent. This survey was conducted by the co-investigators collaboratively. The collaborators are (i) CARE Bangladesh (ii) UNICEF (iii) Government represented by NNP (National Nutrition Program) (iv) SARPV and (v) ICDDR,B. SARPV, because of its extensive experience in diagnosis and treatment of calcium deficient rickets in children was involved in project development. The national survey showed the prevalence of rickets to be 0.99% in children of 1-15 years. In Chittagong division, Chittagong and Cox's Bazar districts had the highest prevalence. In Cox's Bazar district, Chakaria, Maheskhali and Cox's Bazar Sadar Upazila were highly endemic for rickets.

ETIOLOGY OF RICKETS IN BANGLADESH

In Bangladesh, initial studies suggested that vitamin-D deficiency was not a major causal factor in rickets in Bangladesh, and calcium deficiency is assumed to be the primary etiologic factor. Changing cropping patterns in Bangladesh may be contributing to a reduction in dietary intake of calcium: in the last two decades, rice production has greatly increased and crop rotation and milk production have decreased. While underweight and stunting in children have become less common, the diet is less varied than it was three decades ago, and the diet contains less calcium. Boys seem to be more likely to develop rachitic deformities than girls, and rickets is associated with larger family sizes and less maternal education. Rickets is associated with respiratory illness but not with malaria or anaemia. Similarly, toxins, food patterns, and overall nutritional status are not associated with the prevalence of rickets among Bangladeshi children. The relationship between rickets and diarrhoea remains controversial.

TREATMENT OF RICKETS IN BANGLADESH

From 2001 to 2007 Aide Médicale et Development (AMD), SARPV and the CRG treated and followed up more than 3000 rickets children in the Chakaria Disabled Centre. It has been proven that 77% of the children less than 6 years old who have an early stage of active rickets can be treated through nutritional advice. Only 17%, who have greater leg deformities, need medical treatment. Bracing or surgery is needed only for 6% of children with rickets.

5. Project Brief

VISION

SARPV Bangladesh dreams of a "Rickets free Bangladesh".

MISSION

For making the dream of “Rickets free Bangladesh" come true, SARPV Bangladesh has undertaken the "Prevention of Rickets through Nutrition Project" with the assistance of UNICEF, for a rickets free Cox's Bazar in the first leg.

OBJECTIVES

- To raise awareness of the population of the three upazilas on various aspects of Rickets including prevention of childhood Rickets through dietary intake and referral services to special facilities for the Rickets affected children.

- To establish a benchmark, through a baseline survey, in the three project upazilas in identifying and describing the present status of knowledge and attitude about Rickets and related practices, and also of use of iodized salts.

AIMS

- At least 50% of households are aware of rickets in children, its early signs and consequences in terms of disability, its prevention through improved calcium dietary intake, and where to go for treatment.

- Children in 800 families per year (total 2400 families for the 3 years of the program) receive nutritional therapy for rickets.

- At least 50% of households are aware of how to prevent the rickets disease and at least two benefits of iodized salt for school children.

- Coverage of households using iodized salt increased from 21% to 50% in the project area for school Children.

PROJECT AREA

Sadar, Maheshkhali and Chakaria Upazillas of Cox's Bazar District.

PROJECT TENURE

3 years: 2008-2010.

DONOR

UNICEF

6. Project Activities (2008 and 2009)

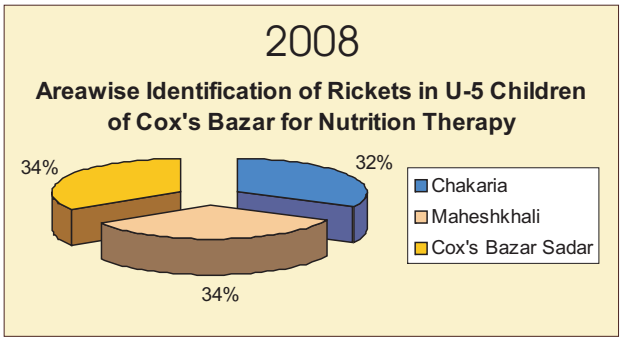
SL No	Activities	Number of Activities		Total	Total Participants
		2008	2009		
1	**Patients identified**	886	855	1,741	47,636
2	**Group Meetings held in patients' houses**	328	328	656	3,180
3	**Video shows held at schools**	24	24	48	24,000
4	**Video shows held in villages**	24	24	48	25,000
5	**Meetings with different stakeholders** (e.g. Imams, Journalists, Students, Teachers, Doctors, Village Leaders etc).	4	4	8	221
6	**Meetings with health department** (Participated by Doctors & Health Assistants in the Upazila Health Complex)	4	4	8	319
7	**Teachers Training on Rickets and Benefits of Iodized Salt** (Participated by Teachers of government and non-government schools in 3 Upazilas)	3	3	6	119
8	**Training of Health Workers on Rickets and Benefits of Iodized Salt** (Participated by Health Assistants, Family Planing Workers, NNP Nutrition Workers in the 3 Upazilas)	3	3	6	117
9	**Sharing Meeting at District level (GO/NGO)**	4	4	8	161
10	**Workshop on Rickets and Benefits of Iodized Salt**	2	2	4	231
11	**Coverage for Print Media Campaign**	6	6	12	132
12	**Household Visits for identification of the Rickets patients.**	6,374	3,153	9,527	47,636
13	**Groups Formed**	82	59	141	705
14	**Staging Live Drama**	3	3	6	
15	**District level Seminar held**	0	1	1	84

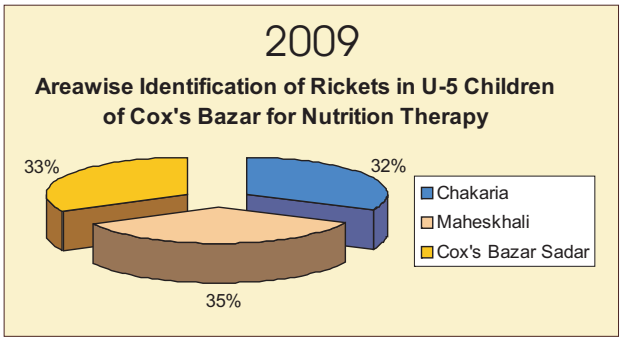
Group Formation Scenario

Area / Upazila	Groups Formed		Members/Patients	
	2008	2009	2008	2009
Maheshkhali	25	24	300	300
Chakaria	28	16	286	274
Sadar	29	19	300	281
Grand Total	82	59	886	855

7. Project Findings

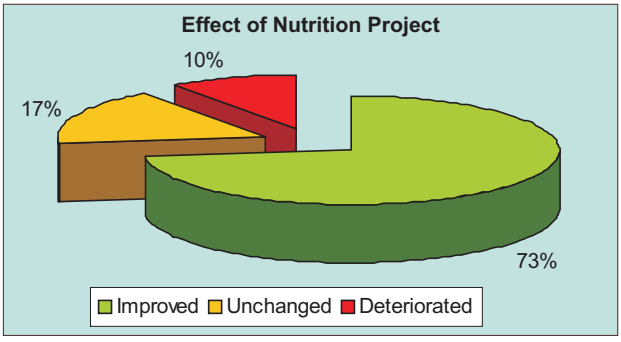
7.1 Condition of Rickets-affected children

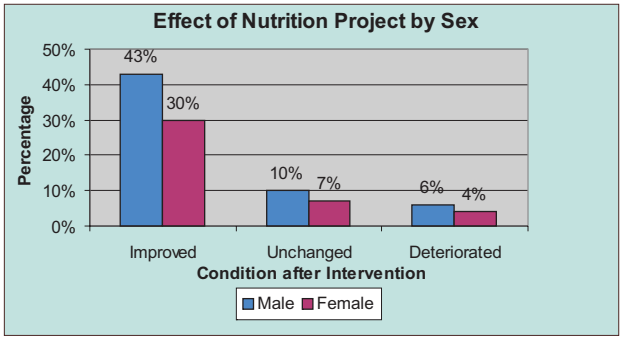




In 2008, 286 from Chakaria, 300 from Mahaskhali and 300 from Cox's Bazar Sadar totaling 886 children under 5 years were identified for nutritional therapy.

In 2009, 274 from Chakaria, 281from Mahaskhali and 300 from Cox's Bazar Sadar totaling 855 children under 5 years were identified for nutritional therapy.

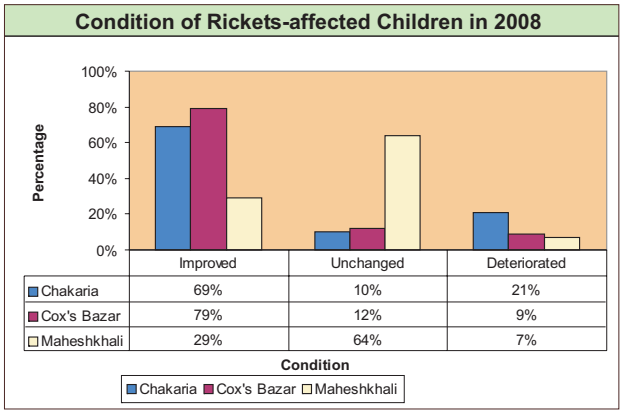




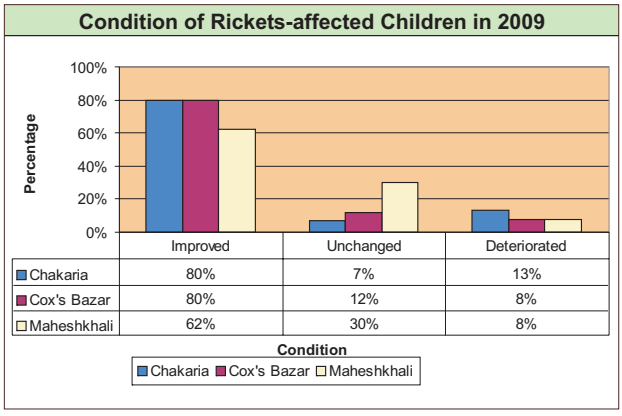
73% (654) was improved, 17% (148) was unchanged and 10% (84) was deteriorated out of 886 ricketic children.

43% were Male and 30% Female among those who improved, 10% were Male and 7% Female among those who remained unchanged and 6% were Male and 4% were female among those whose condition deteriorated.

7.2 Effect of Nutritional Advice



	Improved	Unchanged	Deteriorated
Chakaria	69%	10%	21%
Cox's Bazar	79%	12%	9%
Maheshkhali	29%	64%	7%

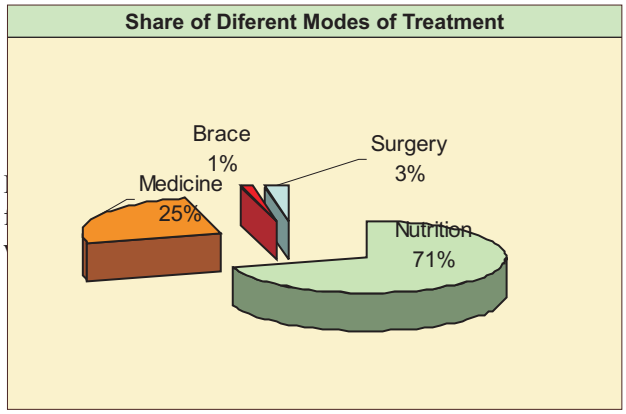


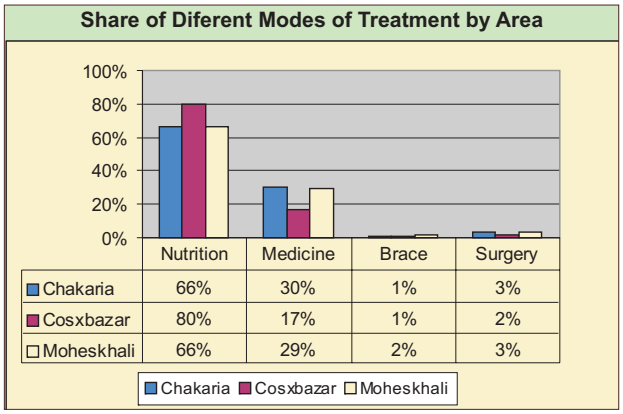
	Improved	Unchanged	Deteriorated
Chakaria	80%	7%	13%
Cox's Bazar	80%	12%	8%
Maheshkhali	62%	30%	8%

Although Rickets was highly endemic in Chakaria, Maheskhali and Cox's Bazar Sadar, the condition of ricketic children was better in 2009 compared to 2008. The improvement rose from 69% to 80% in Chakaria, from 79% to 80% in Cox's Bazar Sadar and from 29% to 62% in Maheshkhali.

7.3 Share of Modes of Treatment vis-à-vis Area

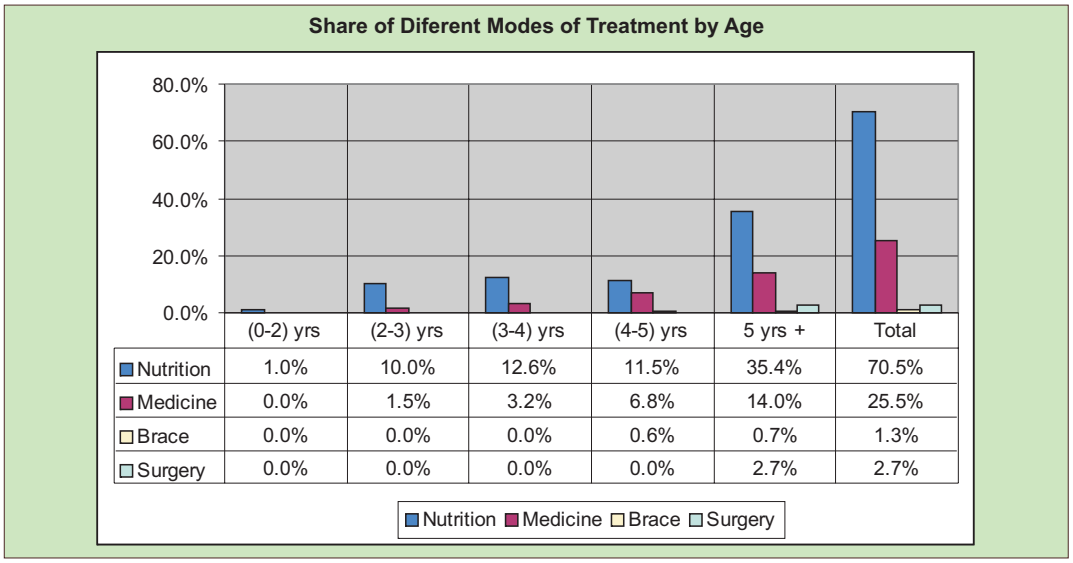
Nutritional advice, medicine (calcium tablet), brace and surgery are different modes of treatment for rickets-affected children. If identified at an early stage, it can be prevented by nutritional advice with calcium tablets alone. It is mentionable that the condition of 70.5% of the children under 5 years of age was improved by only nutritional advice and only 25.4% needed medicine. Brace and surgery were needed for only 1.4% and 2.7% respectively out of 886 children who had greater leg deformities.





66% Children under 5 years in Chakaria, 80% in Cox's Bazar and 66% in Maheskhali had improved through nutritional advice. Medicine was required for 30% children under 5 years in Chakaria, 17% in Cox's Bazar and 2% in Maheskhali- 2% to treat ricketic children under 5 years. A small number of children required brace and surgery.

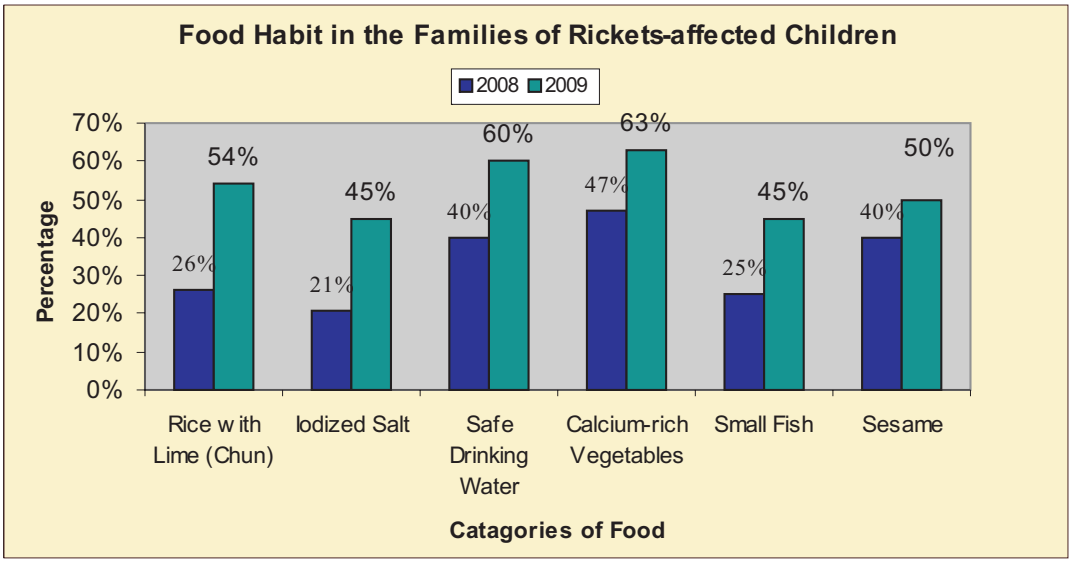
7.4 Age vis-à-vis Modes of Treatment



The above chart reflects that rickets is possible to prevent only through nutritional advice if the children were identified before the age of 5 years. Out of 886 ricketic children, 70.5% received nutritional advice, 25.5% medicine, 1.3% brace and 2.7% surgery. From the data it is shows that the mode of treatment of Ricketic children is likely to be associated with the age of the children.

7.5 Food Habit in the Families of Rickets-affected Children

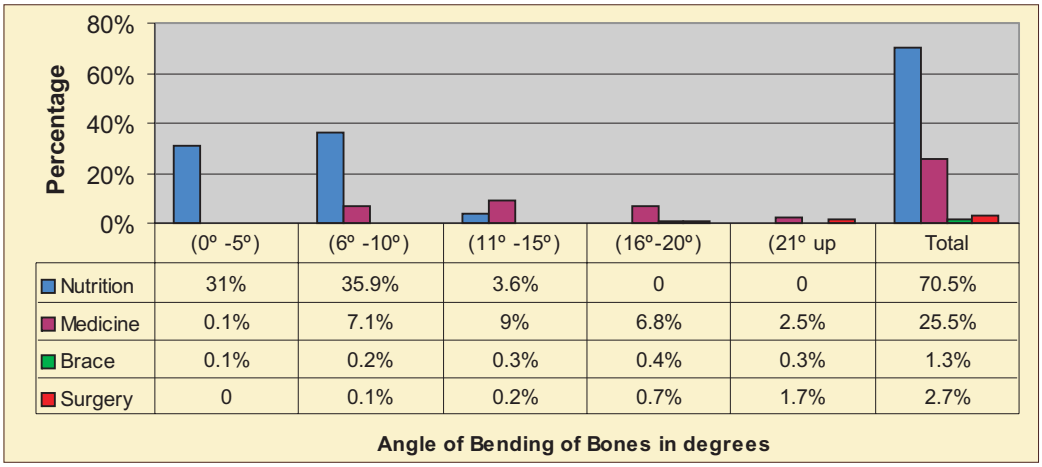
Rickets is a bone-related disease and one of the greatest health problems in Cox's Bazar. SARPV puts emphasis on the food habit of the families of the Rickets-affected children. After the projet intervention by SARPV, major changes were found in the food habit of those families.



In total, 54% families of Rickets-affected children used lime in rice, 45% used iodized salt, 60% used tube well water as safe drinking water. 63%, 45% and 50%families took calcium rich vegetables, small fish and sesame respectively.

7.6 Leg Deformities vis-à-vis Modes of Treatment

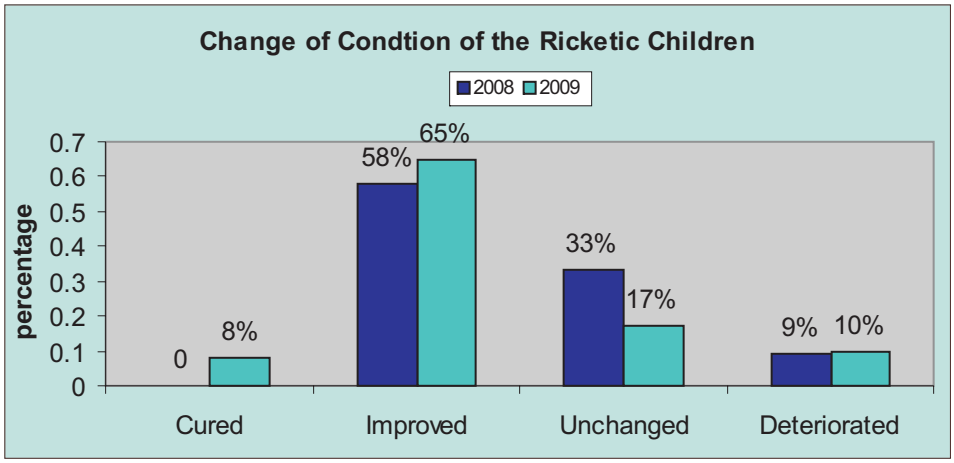
31% children with leg deformities upto 5 degrees, 35.9% with leg deformities of 6-10 degrees and 3.6% with leg deformities of 11-15 degrees, totalling 70.5% were advised for nutritional treatment. Almost none of the children were referred for brace or surgery whose deformities were upto 15 degrees.



	(0º -5º)	(6º -10º)	(11º -15º)	(16º-20º)	(21º up	Total
Nutrition	31%	35.9%	3.6%	0	0	70.5%
Medicine	0.1%	7.1%	9%	6.8%	2.5%	25.5%
Brace	0.1%	0.2%	0.3%	0.4%	0.3%	1.3%
Surgery	0	0.1%	0.2%	0.7%	1.7%	2.7%

From the data it is seen that the mode of treatment of Ricketic children depends on the extent of leg deformities. If the deformity is within 15 degrees and the age is within 5 years, then only nutritional advice can prevent Rickets. But a deformity of more than 30 degrees in 12 year-old children is very likely to make them physically disabled in the end.

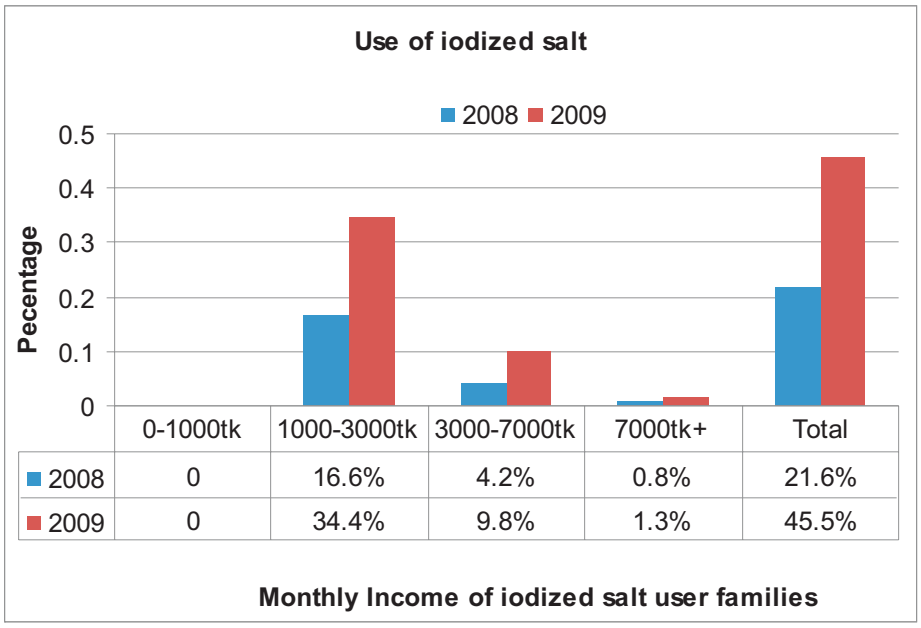
7.7 Change of Condition of the Ricketic Children after Interventions



On the bases of leg deformities and measurement of height and weight, 8% children were observed to be fully curedin 2009. 65% Ricketic children had improved in 2009 compared to 58% in 2008. The percentage of unchanged reduced in 2009 compared to 2008 while the percentage of deterioration remained almost the same.

7.8 Use of Iodized Salt vis-à-vis Family Income

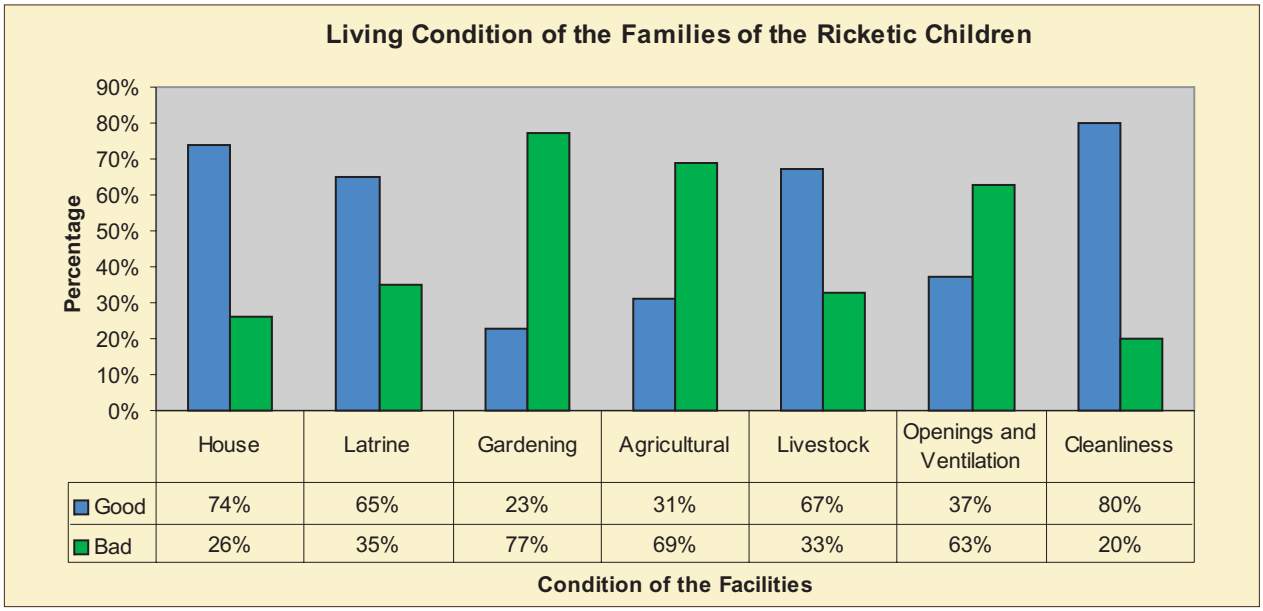
Cox's Bazar has the lowest usage of iodized salt in the country, only 21% compared to the national average of 84% (BBS/UNICEF-2007). One of the major aims of this project was to make the School children under the project area aware of the benefits of iodized salt and to have increased use of iodized salt in their households.



	0-1000tk	1000-3000tk	3000-7000tk	7000tk+	Total
2008	0	16.6%	4.2%	0.8%	21.6%
2009	0	34.4%	9.8%	1.3%	45.5%

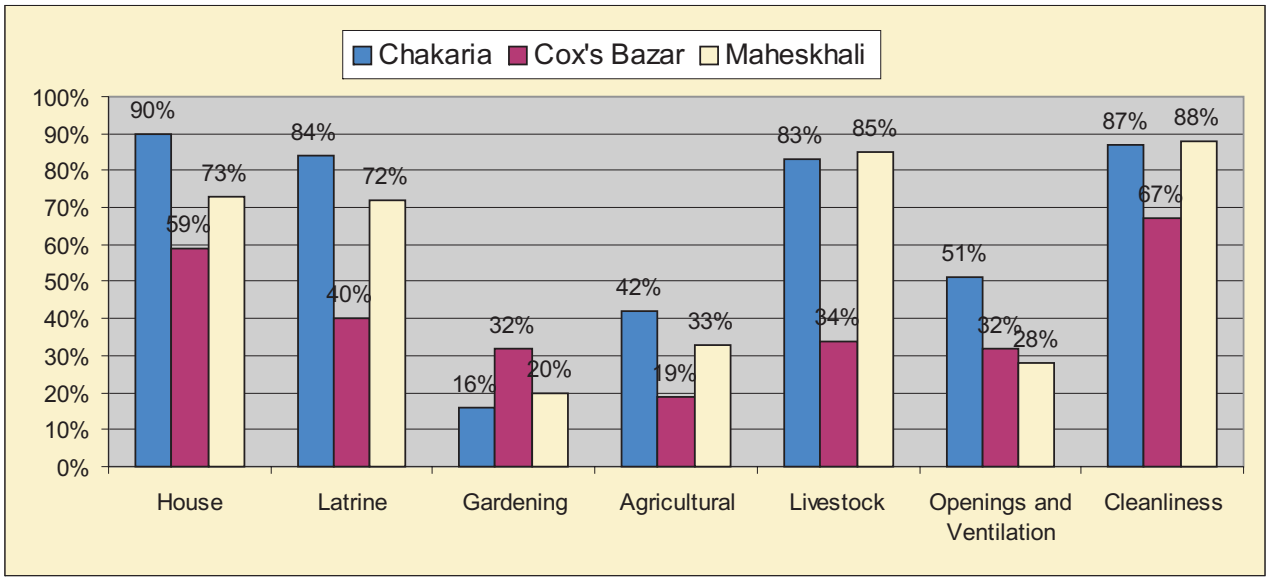
In 2008, only 21.6% (191 families) households used iodized salt. In 2009, the number of iodized salt user families has increased to 45.5 % (403 families). Majority of households has a monthly income of 1,000-3,000/= taka. The most interesting finding was that , in 2008 and 2009, none of the families whose income was within 1,000 taka used iodized salt.

7.9 Living Condition of the Families of the Ricketic Children



	House	Latrine	Gardening	Agricultural	Livestock	Openings and Ventilation	Cleanliness
Good	74%	65%	23%	31%	67%	37%	80%
Bad	26%	35%	77%	69%	33%	63%	20%

As Rickets is likely to have environmental implications, SARPV Bangladesh also gave importance to the living condition of the families of the Ricketic children.



As a whole, the families of the Ricketic children had a faltering status in gardening (23%), agricultural (31%) and openings and ventilation (31%), while majority of the families fared well in house (74%), latrine (65%), livestock (67%), cleanliness (80%). Areawise, Chakaria led the scenario in house, latrine, agricultural and openings and ventilation; Maheshkhali led in livestock and cleanliness; and Cox's Bazar led only in gardening.

8. Challenges faced

- Inadequate number of field staff. Six staff-members have been working in this project in 3 implementing areas. So it is not easy for the staff to regularly supervise ricketic children along with carrying out other awareness raising activities under the project.

- Chakaria, Maheshkhali and Cox's Bazar are the disaster-prone areas of Bangladesh. It is difficult for the people of these areas to make up their losses due to disasters and maintain a sustainable livelihood.

- Although Rickets is apparently a problem related to environment and food habit, due to lack of education and awareness people did not put emphasis on their food habit and living condition to address the issue of Rickets.

- Lack of transportation remains as another majorchallenge to overcome. Houses of a good number of patients are located in very remote areas. As a result it is difficult not only for the field staff to communicate with the patients but also for the patients to access the services from the project outlets.

- Poor families are not interested to use iodized salt as it is costly. One of the findings points out that the families whose monthly income is within 1,000 taka, they are not able to use iodized salt.

- People are more aware of Rickets now but they ask for food support along with medicine because of their inability to pay for the same.

9. Conclusion

Rickets is one of the major causes to make the children disabled which is curable and preventable. SARPV Bangladesh has been working to prevent the disorder using nutritional therapy with the support of UNICEF. But the children who have clinical rickets received higher level of treatment like brace and surgery at the SARPV rickets and disability centre at Chakaria.

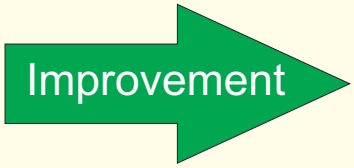
The awareness program has been going on with different groups of stakeholders at different levels including local level communities and GO-NGOs officials and health department personnel etc.

Due to resource limitations the project is being implemented in only 3 Upazilas of Cox's Bazar district Other parts of Cox's Bazar are yet to be reached where people are still in the dark in relation to knowledge about rickets and how to prevent it.

Now Lima can stand on her own feet

Lima, 6 yrs old, daughter of Mr. Nurul Huque lives in Puran Bazar village of Manikpur union under Chakaria upzila of Cox's Bazar district. She was detected with early sign of rickets. She could not move freely as other children of her age. She was advised to take Calcium -rich vegetables, and over a period of 2 years, now her legs are almost normal and she can move on her own.

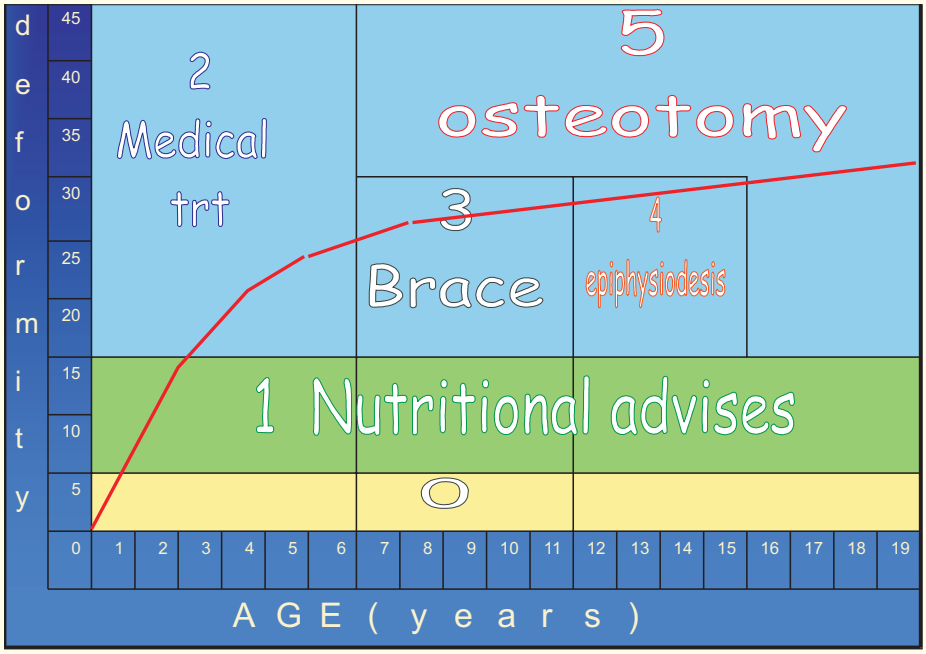
Before Nutritional Advice



After Nutritional Advice

Tools for Identification and Treatment Decision

THE GRADUATED TREATMENT



Using the chart, developed in 2005 by a group of international experts along with Dr. Thierry and his team from France, the course of action regarding treatment is determined considering the age and the degree of deformity of the patient. Modes of treatment include Nutritional advice, Medical Treatment, Long leg brace, Osteotomy (cutting bones) and Surgical Epiphysiodesis (leg lengthening or shortening)

রিকেট্স্ রোগের লক্ষণ

৫ বছর পর্যন্ত শিশুদের মাঝে নিচের লক্ষণগুলোর যে কোন ৩ টি থাকলে তাদের রিকেট্স্ হয়েছে বলে ধরে নিতে হবে

১. উচ্চতা স্বাভাবিকের চেয়ে কম হলে

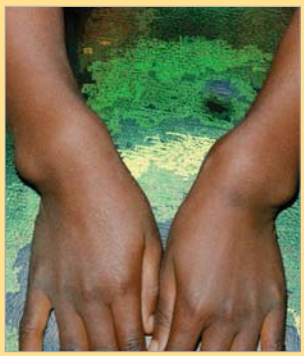
বয়স	ছেলে		মেয়ে	
	গড় ওজন (কে.জি.)	গড় উচ্চতা (সে.মি.)	গড় ওজন (কে.জি.)	গড় উচ্চতা (সে.মি.)
৩ মাস	৫.৮	৬১	৫.৫	৫৯
৬ মাস	৭.৮	৬৭	৭.২	৬৫
৯ মাস	৯.৫	৭২	৮.৫	৭০
১ বছর	১০.৪	৭৬	৯.৫	৭৪
১ বছর ৬ মাস	১১.৮	৮২	১১	৮০
২ বছর	১২.৮	৮৭	১২	৮৫
২ বছর ৬ মাস	১৩.৫	৯২	১৩	৯১
৩ বছর	১৪.৫	৯৫	১৪	৯৪
৪ বছর	১৭	১০২	১৬	১০১
৫ বছর	১৯	১০৯	১৮	১০৮

সূত্র : ইন্সটিটিউট অব চাইল্ড এন্ড মাদার হেল্থ, বাংলাদেশ

২. হাঁটার সময় পায়ে ব্যথা করলে

৩. পাঁজরের হাড় উপরের দিকে বেড়ে গেলে

৪. কব্জির হাড় বেড়ে গেলে



৫. হাঁটু থেকে গোড়ালি পর্যন্ত পা বেঁকে গেলে

বিস্তারিত জানতে হলে:

এসএআরপিভি বাংলাদেশ

ঢাকা: বাড়ি ৫৮৯, রোড ১১, বায়তুল আমান হাউজিং সোসাইটি, আদাবর, শ্যামলী, মোহাম্মদপুর, ঢাকা ফোন: ৮১৯০২৫৩-৪ ই-মেইল: sarpv@bangla.net
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