

INTRODUCTION

The definition of 'Health' proposed by WHO in 1948 as "Health is a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity." It has been estimated that at least 10% of the world's population lives with a disability (WHO, 1981), the majority in developing countries in conditions of poverty. People with disabilities are among the world's vulnerable and least empowered groups. They experience stigma and discrimination with limited access to health care, education and livelihood opportunities. WHO (1980) defines Disability as a "restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being."

International Classification of Functioning, Disability and Health (ICF), states that disability is an umbrella term for impairments, activity limitation or participation restrictions, which result from the interaction between persons with a health condition and environmental factors (e.g., the physical environment, attitudes) and personal factors (e.g., age or gender) (WHO, 2001). Convention on the Rights of Persons with disabilities, states that disability is an evolving concept and results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (UN, 2006).

Community Based Rehabilitation (CBR) as an international initiative was launched by idealistic rehabilitation experts working with the WHO. Its biggest strength is that "it tries to reach all disabled people, especially those who are poorest and in greatest need." It has an all inclusive plan, including government and private initiatives. But, too often, disabled persons still are treated as objects to be worked upon, rather than leaders, organizers and decision makers. One of the biggest challenges for disability workers today is to find ways to link the empowering self determination of the Independent Living Movement with the board outreach to poor people of Community Based Rehabilitation (Werner, 1934).

Physical disability is the problem that arises in operation of physical parts, use and movement in a person due to problems on nerves, muscles and composition and operation activities of bones and joints. e.g., polio, effects of leprosy, muscular dystrophy, problem with joints and spinal cord, club feet, rickets, weakness of bones etc are physical

disability. Short and stunted also fall into this category. The inability to behave in accordance with age and situation and delay in intellectual learning due to problems arising in relation to implementation of intellectual activities like problem arising in the brain and mental part and awareness, orientation, alertness, memory, language, calculation is mental disability. A person who was unable to perform activities or to learn new tasks per the age and environment due to delayed mental development prior to the age of 18 years was said to be mentally retarded. Persons with such problem could hardly manage the daily activities of life like eating, dressing, speaking and going to toilet even with the help of training. Thus, it would be difficult to maintain their health status by themselves.

Those who had more than one type of disability were considered to have multiple/complex disabilities. These included a combination of any types, like both hearing disability and speaking disability, mental retardation with speaking disability or even manipulation with mobility disability. A more complex type of multiple disabilities was cerebral palsy, where damage in the immature brain leads to physical incapacity. This has been classified under complex disability which prevents one from carrying out the normal activities of daily life. It was found that the most prevalent type of disability was multiple disability, which accounted for 31% of the total disabled population in the total population. It was found that the prevalence of multiple disability was 0.51%. The type of multiple disability is moving and manipulation disability accounting for 13.9 percent of the total number of number of retardation with other forms of disability accounted for 8.8% of the cases. The cases of cerebral palsy accounted for 5.9% of the total number of multiple disability cases.

The other types of multiple disability accounted for 18.8% and included those with seeing and hearing disabilities, locomotion and communication disabilities, epilepsy with locomotion disability, epilepsy with chronic mental illness, chronic mental illness with communication disability, and chronic mental illness with communication and locomotion disability (UNICEF, 2001).

Historically, disability was largely understood in mythological or religious terms, e.g. people with disabilities were considered to be possessed by devils or spirits; disability

was often seen as a punishment for wrong doing. These views are still present today in many traditional societies.

In the nineteenth and twentieth centuries, developments in science, and medicine helped to create an understanding that disability has a biological or medical basis, with impairments in the body function and structure being associated with different health conditions. This medical model views disability as a problem of the individual and is primarily focused on cure and the provision of medical care by professionals (Park, 2005). The well known slogan “Nothing about us without us” symbolizes the amount of influence the movement has had. Disabled people’s organizations are focused on achieving full participation and equalization of opportunities for, by and with persons with disabilities. They played a key role in developing the Convention on the Rights of Persons with Disabilities (UN, 2006), which promotes a shift towards a human rights model of disability (WHO, 2010).

Globally, the most common causes of disability include: chronic diseases (e.g. diabetes, cardiovascular disease and cancer); injuries (e.g. due to road traffic accidents, conflicts, falls and land mines); mental health problems; birth defects; malnutrition; and HIV/ AIDS and other communicable diseases. It is very difficult to estimate the exact number of the people living with disabilities throughout the world, however the number is increasing due to the factors such as population growth, increase in chronic health conditions, the ageing of populations, and medical advances that preserve and prolong life (WHO, 2006). Many low and middle income countries face a double burden, i.e. they need to address both traditional problems, such as malnutrition and infectious diseases, and new problems such as chronic conditions.

The sequence of events leading to disability and handicap are due to disease, it results impairment. In other words, an impairment is defined as “any loss or abnormality of psychological, physiological or anatomical structure or function”, e.g. loss of foot, defective vision or mental retardation. Because of impairment, the affected person may be unable to carry out certain activities considered normal for his age, sex, etc. This inability to carry out certain activities is termed “disability.” As a result of disability, the person experiences certain disadvantages in life and is not able to discharge the obligations required of him and play the role expected of him in society which is termed “handicap” (WHO, 1980). The major causes of disabling impairments in the developing countries are

communicable diseases, malnutrition, low quality of perinatal care and accidents. These are responsible for about 70% of cases of disability in developing countries. Primary prevention is the most effective way of dealing with the disability problem in developing countries (Park, 2005).

Community Based Rehabilitation (CBR) is a strategy that seeks to improve the quality of lives of children and people with disability by equalizing of opportunities, promoting and protecting their child rights and improving qualities service delivery. Thus it appeals for the full and coordinated involvement of all level of society.CBR is an internationally accepted strategy for advocate rehabilitation developed by World Health Organization (WHO) and International Community Based Organization (ICO) for developing countries. The strategy of CBR has taken long strides in rehabilitating people with disabilities, making a positive impact on their socio-economic status, health environment and human rights (UNICEF and HMG, 2001).

- **Children with Disability Regarding Status of Health Facilities:**

The United Nations Convention on the Rights of the Child defines a child as “a human being below the age of 18 years under the law applicable to the child, majority is attained earlier.”

All low- income children, whether they are disabled or not, can benefit from improved access to health care associated with insurance coverage. The majority of children with disabilities have the same health care needs as children without disabilities. However, some children with disabilities require special health care services as well as more of the usual health care services.

Children with disabilities can be defined as those who have persistent difficulty doing ordinary childhood activities. These children have physical, behavioral, and emotional problems that can make it difficult for them to participate in sternous activities, get along with others, communicate and learn, or participate in neighborhood or school activities with their peers. Also, these children face difficulty in doing Activities of Daily Living (ADLs). ADLs include bathing, dressing, eating, getting in and out of bed or chairs, using the toilet (including getting to the toilet) and getting around inside the home (Kennedy G.,1998).

Child disability is an emerging global health priority. To address the need for internationally comparable information about the frequency and situation of children with disabilities, UNICEF has recommended that countries include the Ten Questions screen for disability in the Multiple Indicator Cluster Survey (MICS) program (Gottlieb CA., 2009).

The issue of childhood disabilities demands a closer look in context of Nepal; studies have found that disability among children under 5 to be low. The present study indicated a low prevalence of 0.90 among children under 5. It has been noted in previous studies that about 23.9% of the disabilities are present from birth, while 53.6% are due to diseases and 17.6% due to accidents.

In Nepal only one disabled child in a hundred goes to school. The disabled generally live in isolation, with few opportunities for social interaction, employment, education, or expression. The Federation of the Disabled, directed by people with disabilities, promotes the basic rights and opportunities of the disabled and advocates political commitment and rehabilitation of disabilities (UNICEF, 1994).

Nepal has promoted general health facilities for the benefits of population at all levels with the decentralized planning of the health sector there has been expansion of submits at the village level. The health system in Nepal forms a network under the department of health services (DOHS, 1996/97). There are 3187 sub-health posts at the village levels; about 754 health posts functioning in the country. At the electoral constituency level there are 117 primary health care centers.

It has been reported by the DOHS that there are 14 districts public health offices, 74 district hospitals and 61 district health offices at the district level. There are 11 zonal hospitals. These are the existing health services for disabled persons. This extensive networking of the health facilities of the government has been designed to ensure that the majority of the public health and minor treatment problems would be take care of at accessible places and at price the people can afford.

According to Id. Rule 16(2), the law provides some special health facilities for the disabled person's free medicinal examination shall be rendered all the hospitals of the

kingdom. The DPWR clearly directs the reservation of at least two free beds for the treatment of disabled persons in any government hospitals of the kingdom having more than fifty beds (UNICEF and HMG 2001).

Similarly the government may provide essential assistance to those non governmental hospitals which offer free medicine check up's free beds or free treatment for the disabled persons. The DPWA impose responsibility on the government to investigate the general and specific cause of disability and make essential arrangement for the treatment (DNPWA, 1982).

For many children with disability such as CP, parents are heavily involved in self-care activities. Self-care activities, such as bathing, dressing, grooming and eating, can be difficult for children with CP as self-care depends primarily on use of the upper limbs (Van Zelst, 2006). Sensory impairments can make getting dressed and brushing teeth difficult. Along with sensory impairments, motor impairments of the hand are thought to be responsible for difficulties experienced in daily, self-care activities (Arnould, 2008). Children with CP often have oral sensory disturbances meaning that they have too little or too much sensitivity around and in the mouth. An infant with CP may not be able to suck, swallow or chew and this can result in difficulty eating (Klingels, 2010). Overall, children with disabilities focusing multiple disabilities may have difficulty in chewing and swallowing food, along with many other self health care activities due to sensory and motor impairments.

In Nepal, children with disabilities (CWDs) are the most neglected group at all levels in the societies even in their own families. Nepali society still views disability as a penance to the sins committed in previous birth. The families consider that investment in a CWD is not a worthwhile. Regarding health status of CWDs, low attention is paid. Due to lack of awareness about health and negligence by parents in proper health care of CWDs, their health condition is degrading day by day. As a result, they are facing numerous health problems. The survey done on health status of CWDs related to health care practices and its effect in the rehabilitation center is very limited and scanty. It is necessary to carry out the survey to know about health status of CWDs. Hence, a survey study was carried out on health care practices and its effect on health status of children with disability visiting Community Based Rehabilitation Organization (CBRO).

- **Significance of the study**

In the context of Nepal, the issue of children with disability demands a closer look. There is lack of information on the prevalence and severity of the problem in the country regarding disability. Disability is not only the social problem but it can also be linked with medical problem and rehabilitating them has been a major concern for many social organizations as well as government agencies. The study helps these agencies and also for those who want to launch program in the study area.

There are some disabilities that can manage most of their daily activities on their own, while those with severe disabilities have to rely on their caretaker. So, most of the disabled children require either parents or caretakers. Maintenance of health status of CWDs is a major part that parents and caretakers need to be concerned. Thus the study is carried out to explore health care practices regarding personal hygiene, nutrition, immunization and rehabilitation services given to the CWDs by family and caretakers of CBRO.

The study helps to bring awareness on health care practices and its effect to CWDs, parents and caretakers so that most of the children with disabilities could have sound health. Thus, a study was carried in order to investigate the health status of children with disability focusing physical, mental and multiple disabilities up to 18 years of age visiting Patan CBRO were randomly selected during December 2009- November 2010 for the study.

- **Limitations of the study**

- Due to time and budgetary constraints, the study was done only among 61 CWDs including physical, mental and multiple disabilities.
- The study limited clinical examination at the field level. So, it was not possible to identify disabilities of mild, moderate, severe and profound types by non medical (although trained) persons.
- Only through observation and interview with parents and caretakers the effect on health status of CWDs were studied. Thus, the effect of health care practices could

not be studied in detail as most of the CWDs could not express health related problems by themselves.

- The study included CWDs up to 18 years of age. This limited comparison with other studies that include whole population of all age groups.
- The study couldn't relate with recent publications due to difficulty of timely availability of published data from government and other agencies.

II

OBJECTIVES

- **General Objective**

To study the health care practices and its effect on health status of children with disability visiting Patan Community Based Rehabilitation Organization (CBRO).

- **Specific Objectives**

- ❖ To determine the hygienic condition and health related complications of children with disabilities (CWDs).
- ❖ To determine the age and gender wise effect on health status of children with disabilities.
- ❖ To explore the health care and rehabilitation services given to the children by family and the CBRO.
- ❖ To assess Knowledge, Attitude and Practices of children, parents and caretakers on health condition.
- ❖ To recommend mitigation for improvement of personal hygiene of CWDs.
- ❖ To bring awareness on health to children with disabilities, parents and caretakers.

III LITERATURE REVIEW

➤ LITERATURE REVIEW IN GLOBAL PERSPECTIVES

Craviato (1968) mentioned that a number of studies of malnourished young children in underdeveloped countries support the likelihood that malnourishment during the early stages of growth produces impaired intelligence, inadequate integration between seeing and hearing, apathy and limited learning disability. Protein malnutrition contributes to the high death rate in underdeveloped countries; the majority of afflicted children survive, impaired physically and often mentally.

Boyle *et al.*, (1994) reported that 17% of children in the United States had a developmental disability. The prevalence of the individual disabilities ranged from 0.2% for cerebral palsy to 6.5% for learning disabilities. These conditions taken together had a substantial impact on the health and educational functioning of affected children: 1.5 times more doctor visits, 3.5 times more hospital-days, twice the number of school-days lost, and a 2.5-fold increase in the likelihood of repeating a grade in school compared with children without these conditions. The extent of this impact was much greater among children with multiple disabilities or with cerebral palsy, epilepsy or seizures, delays in growth and development, or emotional or behavioral problems. The impact on school performance was most pronounced for children reported to have learning disabilities.

Newacheck and Stoddard (1994) estimated that fewer than 5% of children have multiple (two or more) chronic conditions and that less than 1% of children had three or more such conditions. However, despite this low overall prevalence, some notable features of multiple chronic conditions stand out. Many of the most prevalent condition-pairs were allergy related, and the rates of co-occurrence of these disorders were generally higher than would be predicted on the basis of prevalence rates for the individual conditions. Children with multiple chronic conditions had more mental and physical health problems and used substantially more health services than other children. For example, the prevalence of developmental delay, learning disabilities, and emotional and behavioral problems increased sharply with the number of chronic conditions reported. Notable deterioration in such health status measures as days in bed, school absences, and activity

limitation was also observed with increasing numbers of chronic conditions. Similarly, utilization of hospital and physician services increased in tandem with increasing numbers of chronic conditions.

Kennedy (1998) reported that according to data from the 1994 National Health Interview Survey-Disability Supplement (NHIS-D), more than 5.5 million children (8%) in the United States have disabilities. About 700,000 children with disabilities (12%) lack health insurance coverage, and most of these children (77% or 530,000) live in low income families. More than one quarter (27%) of parents of these children report their children are in fair or poor health. By comparison, only 2% of parents of children without disabilities report fair to poor health.

Saigal *et al.*, (2000), Parents of extremely low birth weight (ELBW) children reported a higher frequency and more complex functional limitations than parents of controls for their own children's health status. Neurosensory impairments were present in 41(27.5%) ELBW children and included 1 or more of the following conditions: cerebral palsy (n=19), hydrocephalus (n=6), significant cognitive impairments (n=14), autism (n=5), unilateral blindness (n=5), bilateral blindness (n=9), and sensory-neural deafness (n=2). Nine of these children had severe cognitive deficits and multiple impairments. One child was in a group home and 4 children were in foster care and the information on these children was obtained from their primary caregivers. Parents of ELBW subjects reported a low proportion of teenagers as having no functional limitations (i.e., perfect health), compared with control parents (34% Vs 60%). One or 2 attributes were reported to be affected in 47 of ELBW subjects, compared with 39% of controls; 3 to 6 attributes were affected in 19% of ELBW teenagers, compared with 2% of control teenagers ($\chi^2=29.1$; $P<.0001$).

Sullivan and Knutson (2000) studied that analysis of the circumstance of maltreatment and the presence of disability established a 9% prevalence rate of maltreatment for nondisabled children and a 31% prevalence rate for the disabled children. Thus, the study established a significant association between the presence of an educationally relevant disability and maltreatment. Children with disabilities are 3.4 times more likely to be maltreated than nondisabled peers. School professionals need to be cognizant of the high base rate of maltreatment among the children they serve. Disability status needs to be considered in national incidence studies of maltreatment.

Ghosh (2004) reported that the most glaring problem is the widespread malnutrition among young children, even though the situation is a little better than before. One-third babies have low birth weight, poor nutritional status of the mother, anemia, and repeated pregnancies contribute to it. Malnutrition among young children is rampant- more in rural (49.6%) than in urban (38.4%), according to the National Family Health Survey, 1998-99. It is well known that mortality is 4-5 times higher among the malnourished children compared to the better nourished children. They are prone to repeated infections and the nutritional status worsens further as a consequence.

Klassen *et al.*, (2004) concluded preschool aged children with conditions that require Neonatal Intensive Care Unit (NICU) care and their family caregivers had poorer health status and health related quality life in a range of domains compared with healthy children. There were also differences within the sample by gestational age and major morbidity. The differences in health were small using the Infant and Toddler Quality of Life questionnaire (ITQOL) and Child Behavior Checklist/ 1.5-5 (CBCL) but larger using the Health Status Classification System Preschool Version (HSCS-PS). The overall response rate for families that we located was 67.1%.NICU children differed from healthy children on the ITQOL in physical abilities, growth and development, temperament/moods, behavior, and general health perceptions, and caregivers differed on both parent-impact scales.

Sricharoen *et al.*, (2008) reported that one of the major risks that affect household incomes is ill health, as it is associated with lower income or higher expenses.

Gottlieb *et al.*, (2009) examined child disability screening and its association with nutrition and early learning in countries with low and middle incomes. A median 23% (range 3-48) of children aged 2-9 years screened positive for disability in the 18 participating countries. For children aged 2-4 years, screening positive for disability was significantly more likely in children who were not breastfed versus those who were (median 36% [9-56] vs. 26% [4-51]) in eight of 18 countries, in children who had not received vitamin A supplementation versus those who had (36% [7-53] vs. 29% [4-50]) in five of ten countries assessed, in children who met criteria for stunting (26% [6-54]) or being underweight (36% [3-61]) versus those who did not (25% [3-42] and 26% [4-43], respectively) in five of 15 countries assessed for stunting and in seven of 15 countries assessed for being underweight, and in those who participated in few early-learning

activities versus others (31% [7-54] vs. 24% [4-51]) in eight of 18 countries. Children aged 6-9 years who did not attend school screened positive for disability more often than did children attending school (29% [2-83] vs. 22% [3-47]) in eight of 18 countries.

Johnson *et al.*, (2009) assessed academic attainment and special educational needs (SEN) in extremely preterm children in middle childhood. Extremely preterm survivors remain at high risk for learning impairments and poor academic attainment in middle childhood. A significant proportion require full-time specialist education and over half of those attending mainstream schools require additional health or educational resources to access the national curriculum. The prevalence and impact of SEN are likely to increase as these children approach the transition to secondary school. Twenty nine (13%) extremely preterm children attended special school. In mainstream schools, 105 (57%) extremely preterm children had SEN (OR 10; 6 to 18) and 103 (55%) required SEN resource provision (OR 10; 6 to 18). Extremely preterm children who entered compulsory education an academic year early due to preterm birth had similar academic attainment but required more SEN support (OR 2; 1.0 to 3.6).

Schieve *et al.*, (2009) studied and found that after adjustment for demographic factors, children with Down syndrome had higher odds, compared with children without mental retardation, of recent food/digestive allergy, frequent diarrhea/colitis, $>$ or $=3$ ear infections in the previous year, very recent head/chest cold, and developmental disabilities other than mental retardation. They had increased odds that approached significance for recent seizures, very recent stomach/intestinal illness, and asthma. They had substantially higher rates (threefold or higher, compared with children without mental retardation) for nearly all health impact and health and special education service use measures. Of note, $>25\%$ of children with Down syndrome needed help with personal care, regularly took prescription medications, had recently seen a medical specialist, and received physical therapy or related therapy. The comparison group with mental retardation without Down syndrome represented many children with multiple serious disabilities who also had high rates of medical conditions and high levels of health impact and service use.

Suzuki and Tsunehiko (2009) examined the current state and social ramifications of disability evaluation in Japan public data from Annual Reports on Health and Welfare, 1998-1999 were investigated. The data suggest that disability evaluation, while

essentially affected by age and impairment factors at a minimum, was impacted more by the assistive environment for disabilities. The assistive environment was found to be closely linked with the welfare support system related to a global assessment in the field of Community based rehabilitation.

➤ **LITERATURE REVIEW IN NEPAL'S PERSPECTIVES**

Devkota (1994) studied the Knowledge, Attitude and Practice at the mothers on maternal and child health care at Pandrung Village in Gorkha district found that about 82% mothers reported that their young child was immunized against diseases. Only 18% children were not immunized.

Shrestha (1994) conducted a research on child health care practices of different ethnic group in Baglung Bazar. The main objectives of the study was to find out maternal health care practices, breast feeding practices, personal hygiene and main health problems under 5 year children. About 88% of the pregnant women were found conscious about their health. Among different ethnic groups, 95% Newar possessed the highest position to follow this practice whereas none of the Majhi's was found to practice n health care.

Giri (1995) studied the Child Health Care practices with relation to Child Mortality in Pyuthan District Nepal. In our country Nepal, standard of environmental is very poor drinking water facilities and inadequate sanitation with regard to waste disposal and housing is extremely unsatisfactory. Water borne diseases like Cholera, Typhoid, Leptospirosis, Giardiasis, Hepatitis B, Bacillary Dysentery, Ascariasis, Whipworm and Hookworm are common in Nepal.

Rajbhandari (1999) mentioned that cerebral palsy has been the most neglected among all types of disabilities. Little has been done for the people with cerebral palsy in Nepal.

Dahal (2000) revealed that majority (53.33%) respondent were the age group of 15-24 years of age. Acquired disability was very common and diseases were the main cause of acquired disability. Poliomyelitis was the main disease which left the disability effects among the respondents though it was curable disease. Institutionalized rehabilitation is very much needed for the severely handicapped who were completely dependent for other people.

Aryal (2001) analyzed the health care practice and its effects on health status of the children under 5 years of age in Magar ethnic group. The main causes of under five child health problems are acute respiratory infection, diarrhoea, malnutrition, lack of health education, improper health facilities and health service, environmental pollution and ignorance of proper child health care practices in any developing countries play a vital role for the improvement of child health status.

UNICEF and HMG (2001) carried out a situation analysis of disability in Nepal. According to it; the prevalence of disability in different age groups among the youngest age groups is low as 0.90%. This could be due to the difficult detection of disability in 0 to 4 years old. It could be due to early deaths of the children with disabilities. It was found that the most prevalent type of disability was multiple disabilities, which accounted for 31% of the total disabled population.

CBS (2002), there were 8,948,587 children aged 0-14 years .Among them 34,630 (0.39%) were disabled. They had been suffered from different types of disabilities such as: physical (42.96%) followed by deafness (24.69%), blindness (13.47%), mentally retarded (10.62%) and multiple disabilities (8.26%). This indicates the prevalence of disability among children is significant in Nepal.

Bhattarai (2003) mentioned Children having health impairments may have different diseases such as Bronchial asthma, tuberculosis, Nephritis, Heart disease and other different diseases like infectious disease, rheumatic fever, chronic diarrhea, eczema, dermatitis, developmental disabilities, psychosomatic disease and leprosy etc.

Sharma (2003) found that the period before completing the age of 5 years was most vulnerable for becoming disabled and accident was the major cause for childhood locomotion disability after birth. Majority (82.5%) had mobility disability. About 34% did not achieve treatment in their households due to poor economic condition.

Duwal (2004) studied on disabled cases that were treated, supervised, monitored and given feedback by CBR project Bhaktapur. The cases taken were under 16years of age. The researcher paid attention on the leading causes of the disability impact of rehabilitation of physically disabled child, social attitude and health related knowledge of the family of the disabled and the educational status of the disabled children.

IV

METHODS

- **STUDY AREA**

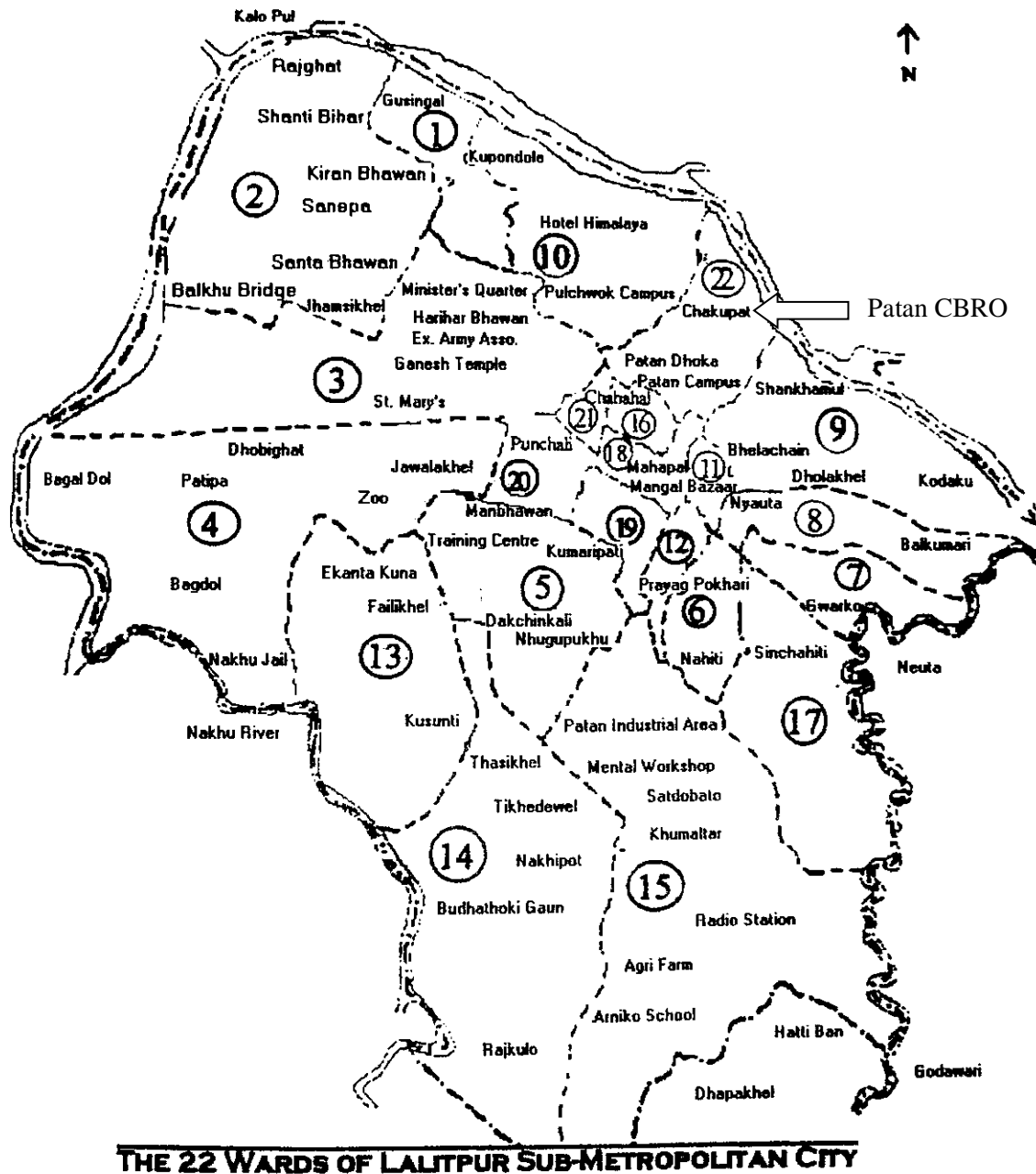
Patan Community Based Rehabilitation Organization (CBRO) is located in Lalitpur district of Nepal. Lalitpur District is one of the Sub-metropolitan cities of Nepal located in South Western part of Kathmandu Valley. It lies 27°40' N longitude and 85°20' E latitude with elevation 457-2831 m. The area occupied by the district is 385 sq. km. The total population of the district is 337,785 and the population density is 877.4/ sq. km. At the time of 2001 Nepal Census, it had a population of 162,991 in 68,922 individual households.

Patan CBRO is a nongovernmental organization, though it is jointly aided by government, INGOs, Community organizations along with some personnel aid. The organization has been rehabilitating focusing more in children with disabilities (CWDs). Patan CBRO has been working in 3 main districts of Nepal i.e., Lalitpur, Kathmandu, and Nuwakot. In the survey done in 2009, there were 505 disabilities in Kathmandu, 1046 in Lalitpur and 160 in Nuwakot. It has been providing different types of services such as Physiotherapy, speech therapy, Occupational therapy, and mass communication, referral services for medicines, operation and assistive devices.

As Patan CBRO facilitates children with disabilities as a target group, this rehabilitation based organization is selected as a study area. The organization operates a Day Care center and education for children with multiple disabilities since 2000 and Children with Intellectual Disability Unit since 2002. Patan CBRO is situated at Chakupat of Lalitpur District. It is providing CBR facilities to Children with Disabilities including physical and mental disability along with multiple disabilities of all the 22 wards of Lalitpur Sub Metropolitan City, 19 Village Development Committees (VDCs) of Lalitpur District, Kathmandu Metropolitan City, 9 VDCs of Kathmandu District and Bidur Municipality and two VDCs in Nuwakot District. So, maximum of these areas except Bidur Municipality and Nuwakot District were covered to carry out the Research work.

The present study was carried out in different areas such as Chapagaun, Sundhara, Thecho, Bajrabarahi, Dhapakhel, Nagdaha, Harisiddhi, Balkumari, Pulchowk and many

other parts of Lalitpur District as well as some areas of Kathmandu Valley including Vimdhunga. The children with physical, mental and multiple disabilities were selected from these areas to carry out home visit.









To collect the information on knowledge, attitude and practices regarding health status of Children with disabilities, their parents were selected. Likewise to know health care practices done to the CWDs, caretakers and teachers of the day care center of Patan CBRO were selected.

Save the Children in Nepal phased out CBR programs financially since the beginning of 2010 but its technical support is still continuing. With this help Patan CBRO is getting success in establishing good relation with all its stake holders including parents of Children with Disability, GOs and NGOs, local governments.





Patan CBRO started to provide day care services since its beginning to support the parents to concentrate their time for livelihood as to facilitate their CWDs. However, the day care center was formally started in 2002 limited to 2 CWDs within Patan area of Lalitpur District. It has come a long way since then and has established itself as a special inclusive school. Day Care and special school unit has a record of serving a total of 186 CWDs till 2010 and continues its services in provision of access to education. Physiotherapy services were one visible activity that brought some positive changes in the situation of all kinds of disability. So, a community based Physiotherapy clinic and counseling center had developed with a vision focused on curative and preventive intervention on causes of disability that would have a holistic approach in awareness and health intervention of disability.

Patan CBRO runs following types of health services program for CWDs, caretakers and parents:

- **Preventive**

-  Orientation on disability
-  Eye Camp
-  General health check-up (teeth, blood pressure, weight, pulse eye, ear)
-  Disability Awareness program
-  Community Rehabilitation Workers (CRW) Training
-  Awareness program on Immunization and nutrition of the child

- **Promotive**

-  Inclusive education related to hand washing behavior and personal cleanliness.
-  Budget allocation
-  Promotion of disability rights
-  Promotion of child Club

- **Curative**
 - ✚ Referral services to hospitals, health posts and clinics
 - ✚ Providing medicines for treatment of Epilepsy

- **Rehabilitative**
 - ✚ Physiotherapy clinic
 - ✚ Teaching ADL skills and vocational training on making candles and cards
 - ✚ Providing assistive devices
 - ✚ Functional and fun activities to CWDs
 - ✚ Counseling
 - ✚ Exposure visit

(Source: Personal contact with director of CBRO)

- **FIELD TECHNIQUES**

The present study was conducted from December 2009 to November 2010 in order to determine the health status of CWDs visiting Patan CBRO. Information on the health care practices and its effect on health status of CWDs was derived with the help of field visits to the respective houses of CWDs and also day care centers of Patan CBRO. Following methods were applied during the study.

- a) **Observation**

Direct Observations were carried out in the CWDs home, their living environment and day care centers for the detailed study of health status of CWDs. Observations were conducted in order to determine the attitudes and behavior of respondents regarding health care practices including personal hygiene and environmental sanitation.

- b) **Interview**

The method of collecting information through personal interviews was carried out in a structured way. Day care centers and special school unit has a record of serving a total of 186 CWDs till 2010. Out of them, 61 CWDs including physical, mental & multiple disabilities were selected during the study. As, most of the children couldn't respond

properly, their parents as well as caretakers involving in the day care centers along with CWDs who could respond were selected as respondents.

A structured questionnaire was prepared basically focusing KAP on health maintenance of the children with disabilities including prophylaxis, current health condition, socioeconomic status, educational status & treatment of their health problems. So by interviewing respondents through a set of structured questionnaire, the hygienic condition and health related complications of CWDs were determined through simple random sampling method.

- **SOURCES OF DATA COLLECTION**

The study was based on both primary and secondary data. Both types of data were collected from following sources.

- **Primary sources**

Primary data was the main source of data to fulfill the objectives of the study. Primary data was collected from the overall research done during study. Collection was mainly done through observation and interview for the study.

- **Secondary sources**

The children's individual records and reports including case report, assessment report, progress report and daily visit records were studied and the secondary data were collected. Besides these, various books, journals, magazines, booklets, brochures, etc., were used for detailed information on related field.

- **STATISTICAL TOOLS**

The collected data were analyzed and interpreted statistically by using following statistical tools and techniques.

→ The Case Fatality Rate (CFR) was measured by using following formula:

$$\text{C.F.R} = \frac{\text{Total no. of deaths due to particular disease}}{\text{Total no. of cases due to same diseases}} \times 100$$

→ For measuring Knowledge, Attitude and Practice (KAP) of the people about Health status, the statistical method was the Chi-Square Test. $\chi^2 = \sum \frac{(O-E)^2}{E}$ with (n-1) d.f. at 95% confidence limit.

Where, O = Observed frequency, E = Expected frequency.

RESULTS

The results of the study conducted during December 2009 to November 2010 in Patan CBRO have been presented based upon observation analysis and questionnaire survey analysis. During the study, 61 CWDs including 7 physical disability, 12 mental disability and 42 multiple disabilities were found. The results of the study have been presented on the basis of health care practices done by CWDs along with parents, caretakers and teachers. The effect of health care practices has been presented on the basis of CWDs either with health problem or without health problem besides disability. The major health problems found were epilepsy, pneumonia, fever, diarrhea and others. The other health related problems are tooth decay, uncontrolled urination, chest pain, heart disease, tuberculosis constipation, bladder stone, weight loss, loss of appetite, difficulty in swallowing, drooling, ear problem, wounds and rough skin of legs, allergy with brightness and shivering of legs.

❖ Root Cause of Disability in CWDs visiting Patan CBRO

It was found that the root causes of Disability in CWDs were almost due to congenital i.e., 42 (68.8%); 3 (4.91%) of them due to accidental case such as fallen down from staircase and from 4th storied building. Sixteen (26.22%) of them had disability due to various diseases such as epilepsy, jaundice, pneumonia, typhoid, unconsciousness, underweight during birth. In some cases, mother suffered from Tuberculosis (T.B) during pregnancy (Fig.1).

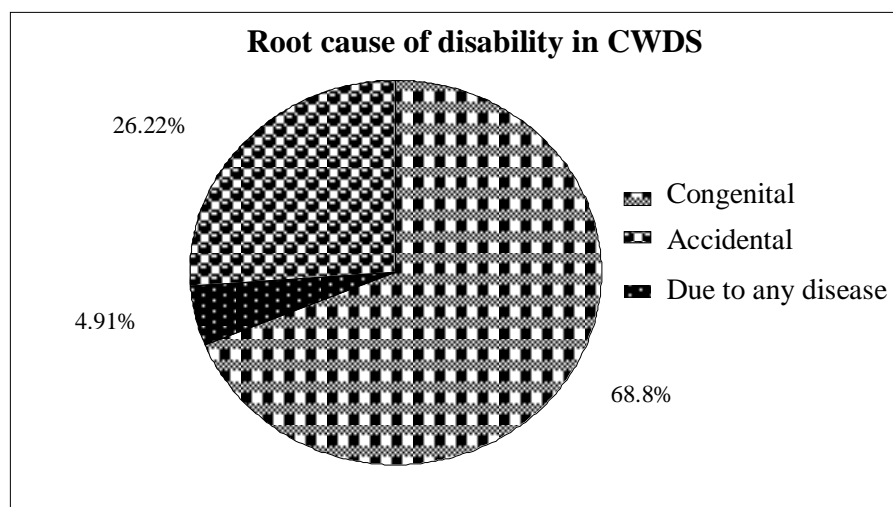


Fig.1: Pie chart showing Root Cause of Disability in CWDs



Plate I: CWDs in day care centre of Patan CBRO

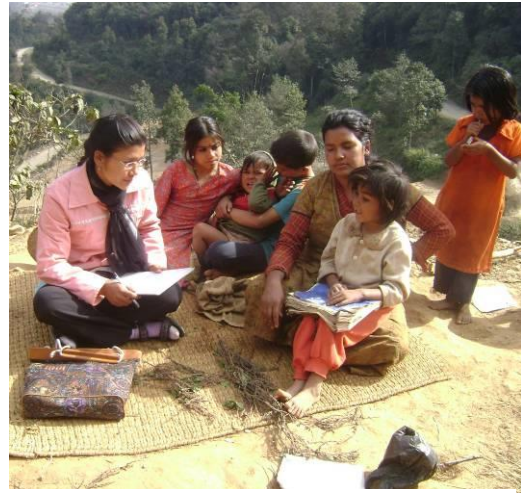


Plate II: In-depth interview with parent of CWD



Plate III: CWDs having teeth decaying problem



Plate IV: CWDs involving in vocational activities of Patan CBRO



Plate V: CWD having eye infection



Plate VI: CWD having pressure /bed sore



Plate VII: CWD having ear infection

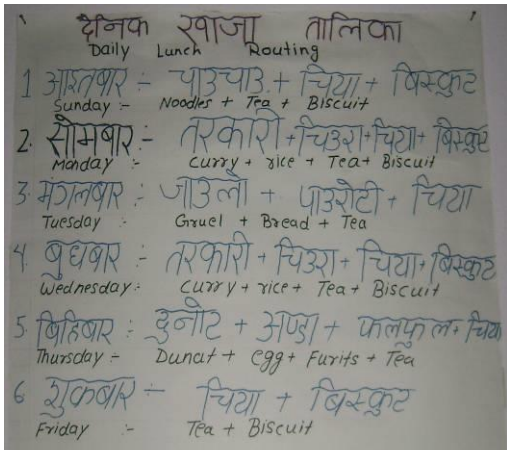


Plate VIII: Daily lunch routine of CWDs of day care centre



Plate IX: Feeding homely made lito



Plate X: Foot deformity with skin infection



Plate XI: Lack of hygienic maintenance during toileting



Plate XII: PT service provided to child with multiple disability



Plate XIII: Group photograph in day care centre with researcher

❖ **Health related problems of CWDs besides disability**

Besides disability, out of 61 CWDs 51 had major health problems such as diarrhea, fever, epilepsy, pneumonia and others. The rest i.e., 10 (16.39%) had no any health problems besides disability. Most of them had problem of epilepsy i.e., 21 (34.4%), others 17 (27.86%), fever 10 (16.39%), pneumonia 2 (3.27%) and diarrhea 1 (1.63%) (Table No. 1). The other health related problems were tooth decay, uncontrolled urination, chest pain, heart disease, constipation, bladder stone, and weight loss. Loss of appetite, difficulty in swallowing, drooling, ear problem, wounds and rough skin of legs, allergy with brightness and shivering of legs. One 16 year child with severe bed sore died after 3 days of the visit in his house.

Table No.1: Health related problems of CWDs besides disability

S.N.	Health problems	No. of CWDs	Percentage (%)
1	Diarrhea	1	1.60
2	Fever	10	16.40
3	Epilepsy	21	34.40
4	Pneumonia	2	3.30
5	Others	17	27.90
6	None	10	16.40
	Total	61	100

❖ **CWDs having severity of the disability problem**

Severity of the problem indicates whether the disability problem is mild, moderate, severe or profound. Maximum CWDs had severity of the problem with mild 22 (36.06%) and minimum was found profound i.e., 5(8.19%). Likewise, 14 (22.95%) were found moderate and 20 (32.78%) were found severe (Fig.2).

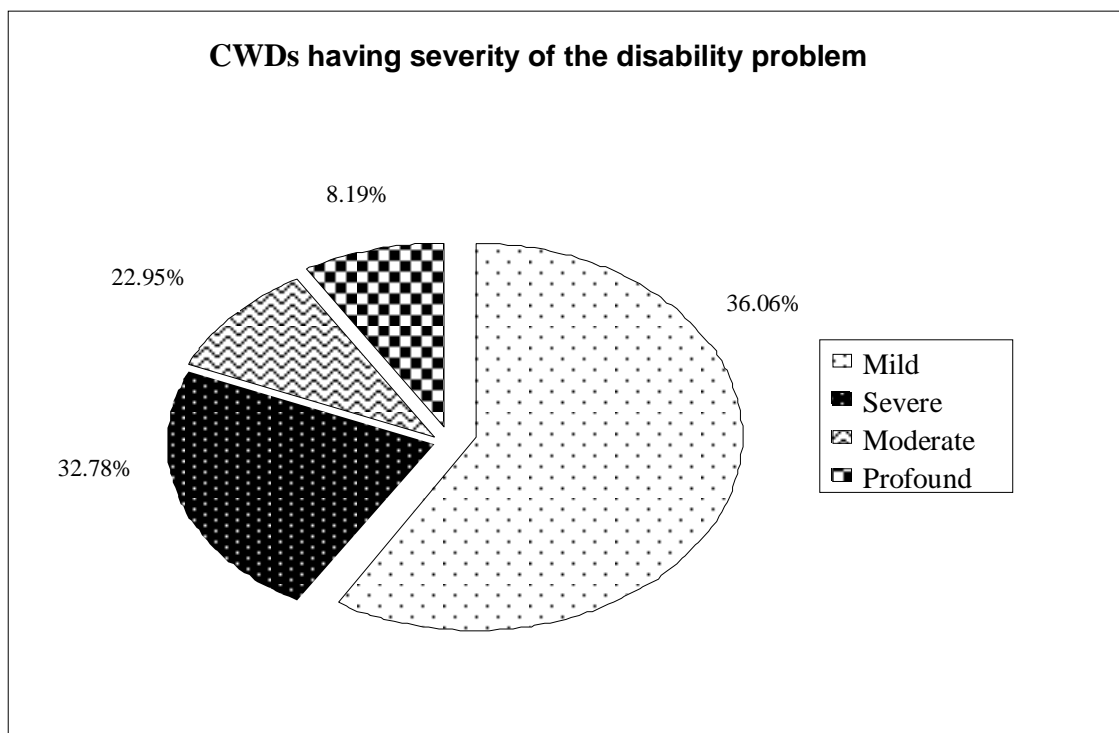


Fig.2: Pie chart showing CWDs having severity of the disability problem

❖ Age and sex wise population of Children with Disabilities (CWDs) with health problem

The age groups of CWDs were categorized into difference of 5 years up to 18 years of age. There were altogether 61 CWDs, out of which 37 were males and 24 were females. The observation indicates that both male and female of these age groups were susceptible to have health problems. The results also clear that the male and female of age group 7-12 years in both sexes have the highest effect of health problem. No female of age group 0-6 years had any health problem (Fig. 3a and b).

Statistically, the result revealed that there was insignificant difference between different age groups and effect on health status ($\chi^2 = 1.15, P < 0.05, d.f. 2$). Likewise, the study also revealed that there was insignificant difference between gender and effect on health status of CWDs ($\chi^2 = 2.44, P < 0.05, d.f. 1$).

Age and sex wise population of CWDs with health problem

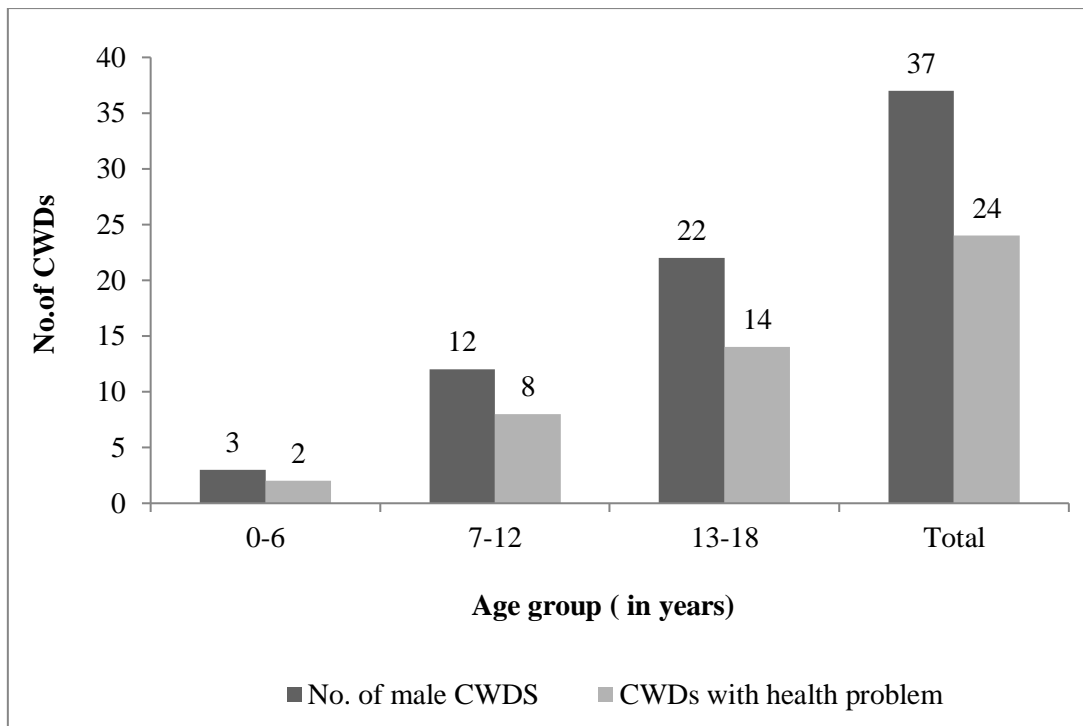


Fig.3a: Graph showing male population of CWDs with health problem

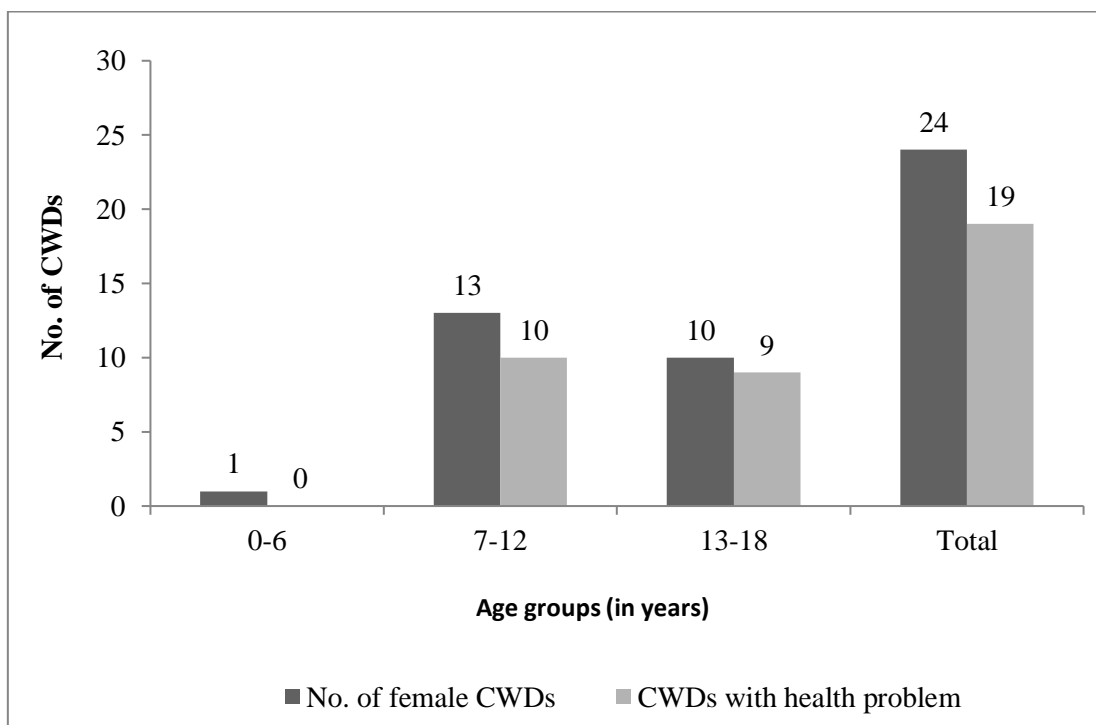


Fig.3b: Graph showing female population of CWDs with health problem

❖ **CWDs having different types of disabilities**

According to ICFDH classification done by Nepal Government (2001), there are 7 types of Disabilities such as Physical, Mental, Speech, Hearing, Deaf and Blind, Visual and Multiple disabilities. During study in Patan CBRO, three types of disability viz., physical, mental and multiple disabilities were selected. There were altogether 61 CWDs. Among 61 CWDs, 7 (11.47%) physical disability, 12 (19.67%) mental disability and 42 (68.85%) multiple disabilities were found. The cases found in Physical disability were arthrogyposis, dwarfism, hydrocephalus, paraplegia, hemiplegia, rickets, kyphosis and foot deformity. The cases found in mental disability were mental retardation, autism, Down’s syndrome, and mental illness.. Likewise the cases found in multiple disabilities were cerebral palsy, speech problem, physical weakness, hard of hearing, microcephalus, spinal deformity, cleft palate, mental illness, hydrocephalus, low vision and deaf. Among 61 CWDs, 0-6 age group had only multiple disability i.e., 4 (9.4%), 7-12 age group had 3(42.86%) physical disability, 3 (25%) mental disability and 21(50%) multiple disability. The age group 13-18 had 4 (57.14%) physical disability, 9 (75%) mental disability and 17(40.6%) multiple disabilities which was maximum in number (Fig. 4).

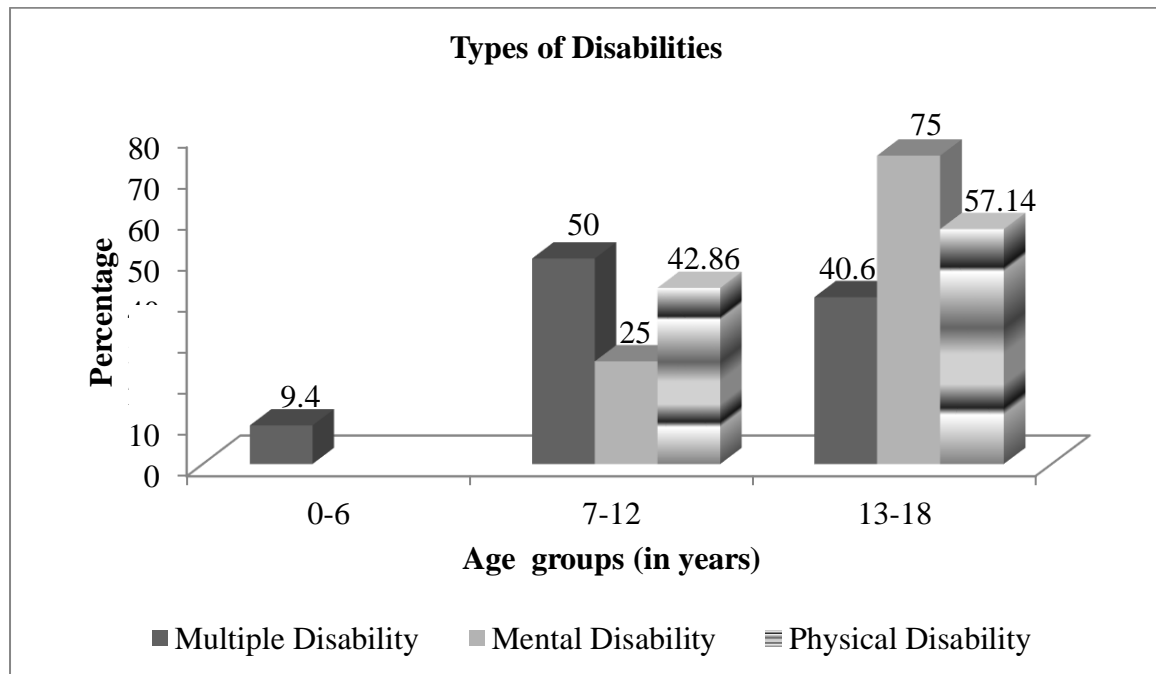


Fig.4: Graph showing different types of disabilities in CWDs

❖ **Educational status of CWDs and its effect on health status**

During the study, literate category includes those who had been to school and acquired either normal or special education. The illiterate category includes those who were not enrolled in school and acquired any form of education. In the study area, maximum 48 CWDs were literate and rests 13 were illiterate. Among the literate CWDs, 12.5% males and 8.33% females had normal education whereas more males i.e., 45.83% had special education (CWDs centered education focusing activities of daily life) and only 33.33% had health problems females had special education. Among literate and illiterate, 34 (70.83%) and 10 (76.92%) respectively (Table no. 2).

Table No.2: Educational status of CWDs and its effect on health status

S.N.	Educational status		No. of CWDs	%	Total	With H.p.	%	
1	Literate	Normal	Male	6	12.5	48	34	70.83
			Female	4	8.33			
	Special	Male	22	45.83				
		Female	16	33.33				
2	Illiterate		Male	8	61.53	13	10	76.92
			Female	5	38.46			

❖ **Income of parents of CWDs and its impact on health status of CWDs**

The main sources of income of the parents of CWDs were business, agriculture and service. It was found that out of 61 respondents i.e., parents of CWDs, 30 (49.18%) had their income from business, 15 (24.59%) from agriculture and 16 (22.22%) from service. By interview it was found that their monthly income ranged from Rs. 8000 to Rs. 25000. Most of their expenditure was to run their family in fooding, clothing, and housing but few amounts is spent for medical services and health facilities of their CWDs. The effect on health status of their CWDs were; 21 (70%) CWDs had health problem whose family were involved in business, 10 (66.66%) had health problem whose family depend upon agriculture and 13 (81.25%) had health problem whose parents involved in service. So, from this result it was interpreted that health conditions of CWDs were better in the

family having the business as their occupation in comparison to agriculture and service (Fig. 5).

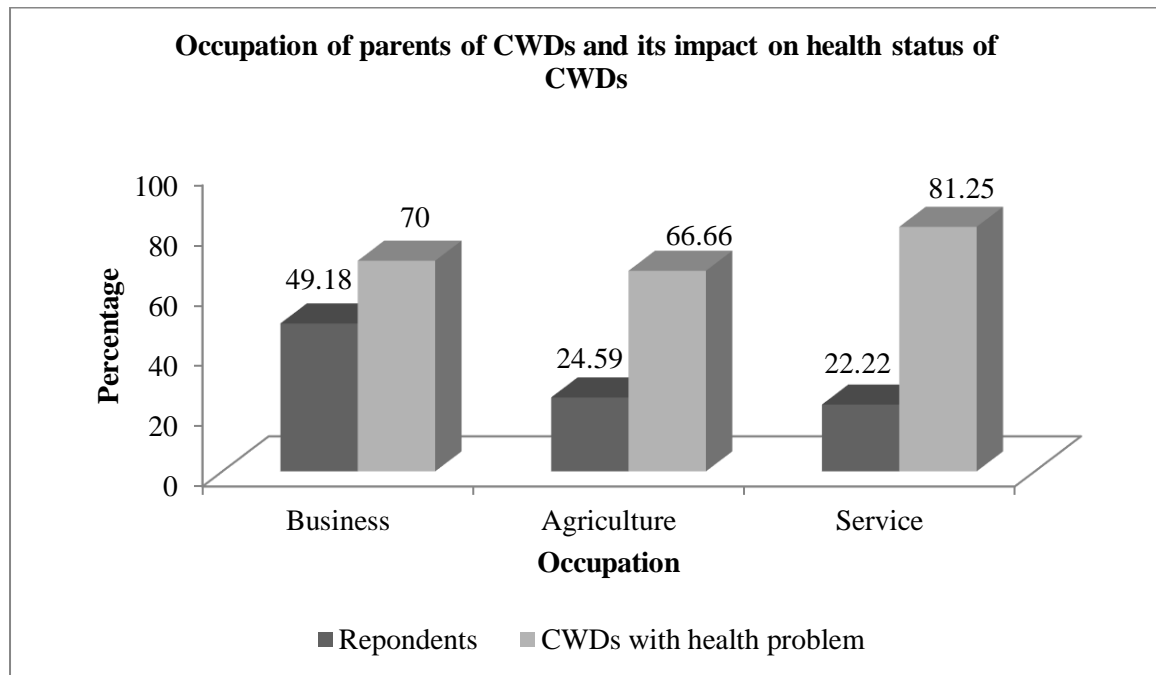


Fig. 5: Graph showing occupation of parents of CWDS and its impact on health status of CWDS

❖ **Vaccines taken by CWDs**

During study period, immunization was found to be effective. Among 61 CWDs, 60 CWDs of all age groups had taken vaccination such as B.C.G, D.P.T, Polio and Measles during under 5 years of age. Among 60 CWDs, one of the CWDs of 10years of age had taken additionally Hepatitis B besides other vaccines. While studying, only an 18 year female child with disability had not taken any vaccination when she was under 5 years of age was found. It was due to lack of knowledge about vaccination of the parents.

❖ **Food taking habit and health status of CWDs**

During the study, out of 61 CWDs, 48 (78.68%) were vegetarian and only 13 (21.31%) were non vegetarian. Among vegetarian and non vegetarian most of them were nourished i.e., 42 (87.5%) and 8 (61.53%) respectively. The malnourished CWDs had health problem such as constipation, weight loss, heart disease, rickets and loss of appetite (Fig.6).Statistically, the result revealed that there was significance difference between food taking habit and its effect on nutrition of CWDs ($\chi^2 =7.34, P<0.05, d.f.1$)

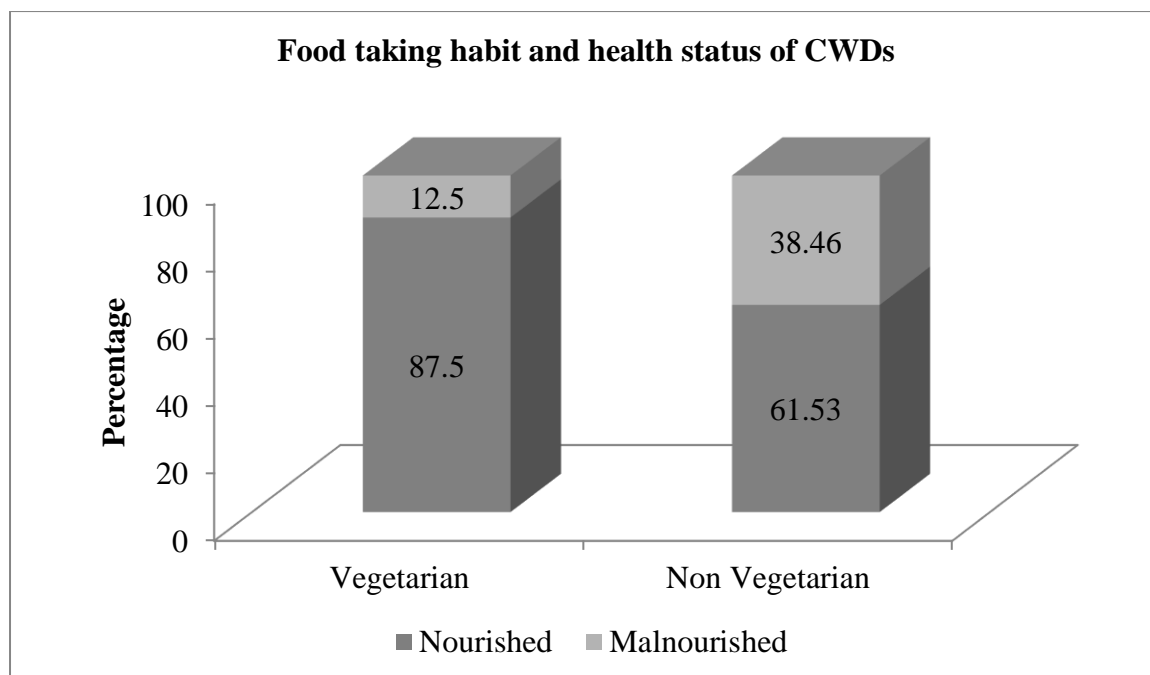


Fig. 6: Graph showing food taking habit and health status of CWDs

❖ Activities of Daily Life (ADL) related to personal hygiene and its effect on health status of CWDs

Most of the parents of CWDs were aware about maintaining the personal hygiene of their children except in brushing teeth due to difficulty for CWDs to do by themselves. The ADL related to personal hygiene among 61 CWDs and its effect on health status was studied (Table No.3).

- Out of 58 (95.08%) who defecated in toilet, 44 (75.86%) had health problem. Out of 3 (4.91%) who defecated in open field, 2 (66.66%) had health problem like stomach problem, diarrhoea and vomiting.
- 25 (40.98%) CWDs brushed teeth daily and 36 (59.01%) CWDs didn't brush daily as they couldn't do by themselves. So, most of them i.e., 20 (55.55%) who didn't brush teeth had tooth decay problem.
- 46 (75.40%) CWDs trimmed nails when dirty and long whereas 15 (24.59%) CWDs didn't trim their nails. 60% of CWDs who didn't trim their nails had health problem like fever and diarrhoea.
- 47 (77.04%) CWDs were found combing their hair daily with the help of their parents. Out of 14 (22.95%) CWDs who didn't comb their hair daily, 10 (71.42%) had health problem such as fever and even found with head louse (*Pediculus humanus capitis*).

- 48 (78.68%) CWDs were found wearing clean clothes and 13 (21.31%) CWDs were found wearing dirty clothes. 53.84% of CWDs wearing dirty clothes had health problems such as rough skin, wounds, itching, and irritation of skin.
- Most of the time CWDs require somebody to take their bath. Due to lack of proper care by the parents, most of them i.e., 51 (83.60%) CWDs took bath once a week, 8(13.11%) CWDs once a month and only 2 (3.27%) CWDs took bath daily. Those who took bath once a week and once a month had 76.47% and 50% health problem respectively. CWDs with health problems such as skin disease, fever and pediculosis.

Table No. 3: ADL related to personal hygiene and its effect on health status of CWDs

Activities of Daily Life (ADL)		Total No. of CWDs	CWDs with health problem	
			No.	%
Toileting	Toilet	58	44	75.86
	Open field	3	2	66.66
Brushing teeth	Yes	25	20	80
	No	36	20	55.55
Trimming nails	Yes	46	33	71.73
	No	15	9	60
Combing hair daily	Yes	47	34	72.34
	No	14	10	71.42
Clothing	Clean	48	37	77.08
	Dirty	13	7	53.84
Bathing	Once a week	51	39	76.47
	Daily	2	1	50
	Once a month	8	4	50

❖ Hand washing behavior of CWDs and their parents in relation to its effect on health status of CWDs

Regarding washing hands, out of 61, maximum CWDs i.e., 54 (88.52%) and their parents washed their hands after going to latrines. Among them, 59.25% had health problem. 52 (85.24%) washed their hands before cooking /eating food and 61.53% had health problem. 39 (63.93%) of them washed hands with soap and clean water and 56.41% were found to have health problem. 19 (31.14%) washed hands with water only and 73.68% had health problem. 15 (24.59%) washed hands before and after caring of child. Among them, 60% had health problem. The most common health problems found among CWDs were diarrhea, pneumonia, fever and jaundice (Table No. 4).

Table No. 4: Hand washing behavior of CWDs and their parents in relation to its effect on health status of CWDs

S.N	Washing hands	No. of CWDs and parents	CWDs with H.p.	
			No.	%
1	With soap and clean water	39	22	56.41
2	With water only	19	14	73.68
3	Before and after caring of child	15	9	60
4	After going to latrines	54	32	59.25
5	Before cooking /eating food	52	32	61.53

❖ **Water drinking behavior in relation to health status of CWDs**

Due to practice of drinking water directly from the source such as tap and well without any treatment, 23(58.97%) had health problem out of 39 CWDs. 77.77% had health problem among CWDs using boiled water. Those using filtered and chlorinated water had 50% and 66.66% health problem respectively. Nausea, vomiting, stomach problem, common cold, sore throat, cough and ear infection were the health problems found in CWDs who had practice of drinking water without treatment (Table No.5).

Table No. 5: Water drinking behavior in relation to health status of CWDs

S.N	Method of drinking water	No. of CWDs	With H.p.	%
1	Boiled	9	7	77.77
2	Filtered	10	5	50
3	Chlorinated	3	2	66.66
4	None	39	23	58.97
5	Total	61	37	60.65

❖ **Management of waste products by the family of CWDs and its effect on health status of CWDs**

Due to lack of knowledge and proper disposal area, the waste products coming from CWDs house were thrown either in open field or ditches near by the house. It was found that 31 (50.81%) CWDs family managed waste products throwing in the container sent by Sub-Metropolitan city of Lalitpur district and 20 (64.16) had health problem. 30 (49.1%) threw waste products near by the house and 23 (76.66%) had health problem. Fever, diarrhea, vomiting, nausea, skin irritation, common cold and cough were the health problems found in CWDs (Table No. 6).

Table No. 6: Management of waste products by the family of CWDs and its effect on health status of CWDs

S.N	Waste management	No. of respondents	CWDs with health problem	
			No.	%
1	Container	31	20	64.16
2	Near by the house/ open field	30	23	76.66
	Total	61	43	70.49

❖ Changes observed regarding health status of CWDs after getting rehabilitation services provided by Patan CBRO

Most of CWDs visited Patan CBRO regularly i.e., 33 (54.09%). Among them after getting rehabilitation services health conditions of 25 (75.75%) were found improving; 8 (24.24%) had no change and none of their health condition deteriorated. Twenty three (37.70%) CWDs visited occasionally and 15(65.21%) had improving health condition, 7(30.43%) with no change and 1(4.34%) had deteriorated health condition. Five (8.19%) CWDs visited irregularly i.e., they visited according to need. Among them, 2 (40%) of their health condition deteriorated.

Patan CBRO provides instructions and activities to be followed by CWDs. Among 61, 45 (73.77%) were found to be followed and 16 (26.22%) did not follow the instructions and activities provided by the Patan CBRO due to time limitation of the parents, low socioeconomic status, and minimal improvement in long time of rehabilitation. Those who followed the instruction and activities were found to have improving health condition i.e., 30 (66.66%) but those who didn't follow had no any improvement in their health condition (Table No. 7).

Table No. 7: Changes observed regarding health status of CWDs after getting rehabilitation services provided by Patan CBRO

S. N.	CWDs getting rehabilitation services		No. of CWDs	Changes observed					
				Impro.	%	N.c.	%	Det.	%
1	Visiting Patan CBRO	Regular	33	25	75.75	8	24.24	0	0
		Occasional	23	15	65.21	7	30.43	1	4.34
		Irregular	5	1	20	2	40	2	40
2	Following instructions and activities	Yes	45	30	66.66	13	28.88	2	4.44
		No	16	0	0	9	56.25	7	43.75

❖ **Case fatality rate (CFR) of children with disabilities visiting Patan CBRO during the study period**

The Case Fatality Rate (CFR) was measured by using following formula:

$$CFR = \frac{\text{Total no. of deaths due to particular disease}}{\text{Total no. of cases due to same diseases}} \times 100$$

Since, there was 1 death out of 61 children with disabilities. The cause of death was mainly due to severe bed sore besides multiple health problems such as physical weakness, visual disability, ear infection, cerebral palsy etc.

Thus the case fatality rate (CFR) of children with disabilities visiting Patan CBRO was found 1.63%.

❖ **Positive effect on health status of CWDs after visiting Patan CBRO**

Out of 61 CWDs, the most common health problems found during study were epilepsy, tooth decay, and others such as fever, diarrhea, common cold, constipation etc. The positive effect on these health problems were assessed and analyzed based on health care practices given to CWDs by Patan CBRO.

- ***Epilepsy***

Among 21(34.40%) CWDs having epilepsy, 14(66.66%) had controlled epileptic attacks and seizures as positive effect. The effect was due to providing antiepileptic drugs in appropriate dose by Patan CBRO.

- ***Tooth decay***

Among 20(32.78%) CWDs having tooth decay problem, 5(25%) had improved condition i.e., with no further complication. The effect was due to regular cleanliness of teeth and mouth of CWDs. The caretakers had practice of rinsing mouth with clean water after feeding to them.

- ***Other health problems***

Other health problems like fever, diarrhea, common cold, constipation, chest infection etc were found to be reduced as positive effect in 10(50%)out of 20(32.78%) CWDs. The positive effect was due to regular supply of nutritious and hygienic food, personal cleanliness and sanitation of rooms of day care centre of Patan CBRO.

- ❖ **KAP of respondents on health status of CWDs**

The respondents were parents, caretakers and some CWDs as well. To assess knowledge, attitude and practice on health condition, they were interviewed with a set of structured questionnaire.

- **Knowledge of respondents regarding health status of CWDs**

The respondents who had no knowledge regarding personal hygiene, environmental sanitation, immunization and nutrition were found 9 (14.75%) and the rest 52 (85.24%) had knowledge on them.

- **Attitudes of respondents regarding health care practices (immunization, nutrition and environmental sanitation)**

Regarding immunization, out of 61 respondents, 58 (95.08%) showed positive attitude towards taking vaccines under 5 years of age viz., B.C.G, D.P.T, polio, measles. Out of 61 respondents, 39 (63.93%) had knowledge about eating nutritious food and 32 (52.45%) had knowledge about waste management regarding environmental sanitation (Table No. 8).

Table No. 8: Attitudes of respondents regarding health care practices

S.N.	Health care practices	Positive attitude		Total
		No.	%	
1	Immunization	58	95.08	61
	Taking vaccines under 5 years of age			
2	Nutrition	39	63.93	
	Eating nutritious food			
3	Environmental sanitation	32	52.45	
	Managing waste products			

▪ **Attitudes of respondents regarding personal hygiene**

Out of 61 respondents, it was found that the parents and caretakers had positive attitude regarding personal hygiene of their children with disabilities. It was found using toilet 50 (81.96%), brushing teeth 25 (40.98%), trimming nails when long and dirty 46 (75.40%), combing hair daily 47 (77.04%), wearing clean clothes 48 (78.68%), bathing daily 4 (6.55%), drinking either boiled, filtered or chlorinated water 22 (36.06%). Regarding washing hands, the respondents with positive attitude were with soap and clean water 39 (63.93%), after going to latrines 30 (49.18%), before and after caring of child 15 (24.59%) and before cooking/ eating food 44 (72.13%) (Fig. 7).

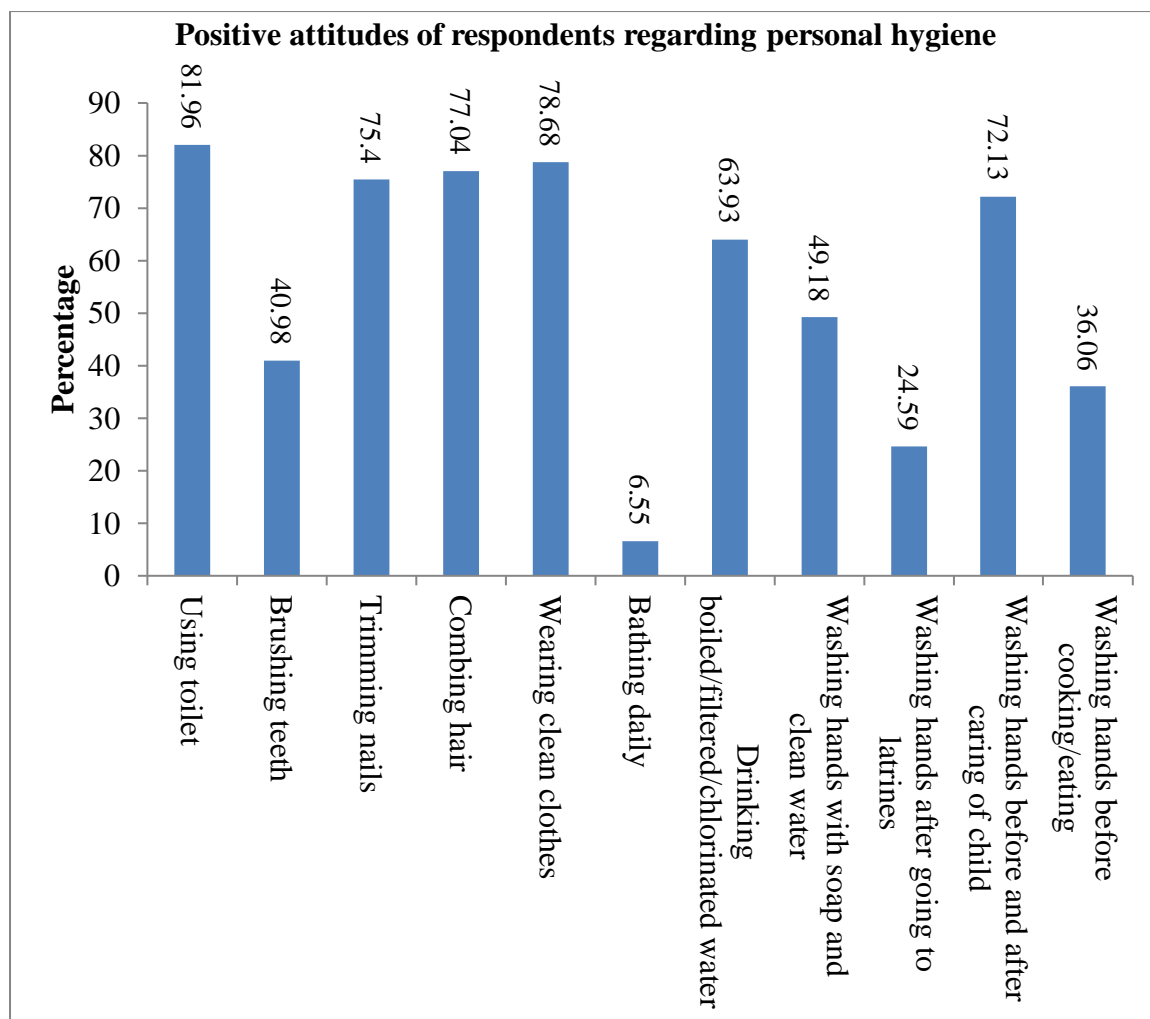


Fig. 7: Graph showing positive attitudes of respondents regarding personal hygiene

▪ **Health Care Practice/behavior of caretakers on health status of CWDs**

According to caretakers working at Patan CBRO, the day care center has been established especially focused on children with multiple disabilities to provide rehabilitation services. Regarding sanitation of the day care center, the rooms of day care center were not large/open enough whereas well ventilated with sufficient sunlight except the room of play group. However, all the rooms were cleaned daily. The drinking water being used for the CWDs were filtered. At 1 p. m, they provide food for CWDs. The different types of food given were rice mixed with daal or milk, lito, bread, banana and other seasonal food which were soft and easily swallowed.

VI

DISCUSSION AND CONCLUSION

The present study aimed to investigate the health care practices and its effect on health status of children with disability visiting Patan CBRO. To study the health care practices and its effect, 61 CWDs were selected of age up to 18 years. Among them, 37 were males and 24 were females. Based upon structured questionnaire and observation, the health care practices of CWDs regarding ADL related personal hygiene, environmental sanitation, nutrition, immunization, educational status and socioeconomic status were studied. The effect of these health care practices was determined by whether the CWDs had health problem or not besides disability problem. The major health problems found among CWDs were epilepsy 21 (34.4%), fever 10 (16.40%), pneumonia 2 (3.30%), diarrhea 1 (1.60%) and others 17 (27.90%). The other health related problems are tooth decay, uncontrolled urination, chest pain, heart disease, constipation, bladder stone, weight loss, loss of appetite, difficulty in swallowing, drooling, ear problem, wounds and rough skin of legs, allergy with brightness and shivering of legs. Most of them had problem of epilepsy i.e., 21(34.4%) whereas a survey done by UNICEF and HMG Nepal (2001) showed that epilepsy accounted for 13.3% of the disabled persons. Patan CBR (2005) also studied that out of 133 CWDs found in the 7 VDCs of Lalitpur district, 50% (3 out of 6) suffered from epilepsy which resembles to the present study.

Out of 61 CWDs, 7 (11.47%) had physical disability, 12 (19.67%) had mental disability and 42 (68.85%) had multiple disability. The most common type of disability in CWDs was the multiple disabilities which are almost similar to the result revealed by UNICEF and HMG Nepal, (2001) i.e., most of the people had multiple disabilities, which accounted for 31% of the total disabled persons in the country. CBS, (2002) also showed that children aged 0-14 years suffered from physical disability (42.96%), mentally retarded (10.62%) and multiple disabilities (8.26%). Boyle *et al.*, (1994) reported that 17% of children in the United States had a developmental disability. The prevalence of the individual disabilities ranged from 0.2% for cerebral palsy to 6.5% for learning disabilities. These conditions taken together had a substantial impact on the health and educational functioning of affected children. The extent of this impact was much greater among children with multiple disabilities or with cerebral palsy, epilepsy or seizures,

delays in growth and development, or emotional or behavioral problems which were quite similar to the present study.

According to the present study, the root cause of disability in CWDs were due to congenital (68.8%), accidental (4.91%) and due to diseases (26.22%) such as jaundice, pneumonia, typhoid, unconsciousness, malnutrition, epilepsy and in some cases mother suffered from tuberculosis during pregnancy which is almost similar to the result revealed by Dahal, (2000). He revealed that acquired disability was very common and diseases were the main cause of acquired disability. Sharma, (2003) found that accident was the major cause for childhood locomotion disability after birth. Craviato, (1968) mentioned that protein malnutrition contributes to the high death rate in under developed countries; the majority of afflicted children survive, impaired physically and often mentally.

The age group wise health care practices and its effect on health status of the present study revealed that there was no significant difference between different age groups and effect on health status ($\chi^2 = 1.15$, $P < 0.05$, d.f. 2). Similarly, 24 (64.86%) male and 20 (83.33%) female had health problem gender wise. This data statistically revealed that the gender and the effect on health status of CWDs are not associated ($\chi^2 = 2.44$, $P < 0.05$, d.f. 1). Majority of them had health problem such as epilepsy, pneumonia, fever, diarrhea, tuberculosis, heart disease, and many other symptomatic problems. Some of the diseases found in the present study are similar to the study done by Bhattarai, (2003) i.e., children having health impairments may have different diseases such as bronchial asthma, tuberculosis, nephritis, heart disease and other infectious disease, rheumatic fever, chronic diarrhea, eczema, dermatitis, developmental disabilities, psychosomatic disease and leprosy.

Ghosh, (2004) reported that one third babies have low birth weight, poor nutritional status of the mother, anemia, and repeated pregnancies contribute to it. The malnourished children are prone to repeated infections and the nutritional status worsens further as a consequence. Likewise, Collis and James, (1967) mentioned that it is not easy to get enough protein from a vegetarian diet. Compton and Warren, (2005) mentioned that constipation is the most common dietary related disease in childhood. It is a condition of hard and/or infrequent bowel motions. It is caused by a lack of insoluble fiber in the diet, mainly due to the consumption of a high percentage of refined foods. Coronary heart

disease is associated with a diet in high saturated fats and cholesterol. These studies resemble to the present study that 12.5% of vegetarian and 38.46% of non vegetarian were found malnourished and they had health problems such as constipation, weight loss, heart disease, rickets and loss of appetite. The data statistically revealed that there was significant difference between food taking habit and the effect on nutrition of CWDs ($\chi^2 = 7.34, P < 0.05, d.f. 1$).

Ghosh, (2004) revealed that immunization was provided against tuberculosis, diphtheria, pertussis, poliomyelitis, measles and neonatal tetanus. Pregnant women were given immunization against tetanus. Reports indicated that 25% of children had not received an immunization at all. According to the field study done by Patan CBR (2005), 17.3% were not vaccinated. However all the CWD under age 14 were found to be immunized showing the effectiveness of the vaccination program launched by HMG. This result shows somewhat close relationship with the present study.

Gartoulla, (2008) mentioned that the socioeconomic status of a population has significant impact on the incidence of disease. It has been suggested that people living in higher socioeconomic status have high incidence of acute illness and people living in low socioeconomic have chronic diseases depends upon their needs and according to their cultural sites differing at another and from one caste group to another. The level of education, social norms opportunities all influence the health and disease pattern of population. Kennedy (1998) reported that about 700,000 children with disabilities (12 %) lack health insurance coverage, and most of these children (77 % on 530,000) live in low income families. More than one quarter (27 %) of parents of these children report their children are in fair or poor health. This result shows somewhat similar result to the present study.

Patan CBR, (2005) studied the age wise school attended by CWDS getting normal education with 43.8%. Regarding gender wise literacy rate 64.9% males were literate whereas only 35.1% females were literate. Only 8.8% and 7% PWDs had child education and special education respectively. But, during the study more CWDs visiting Patan CBRO were almost admitted in Day care centre providing special education.

Children with physical disability of age group 13-18 had 75 % health problems. The same age group of mental disability had 77.77 % health problem. In case of multiple disability,

CWDs with age group 7-12 had 76.19 % health problems. The main causes of health problem were due to lack of health education, sanitation, personal hygiene, lack of treatment of disease in time, nutrition, improper child care practices done by parents and care takers and also CWDs themselves due to disability problem in them. This result of the present study is similar to the study done by Aryal, (2001). He conducted similar study and analyzed that the main causes of less than five years old child health problems are acute respiratory infection, diarrhea, improper health facilities and health service, environmental pollution and ignorance of proper child health care practices in any developing countries. The consciousness on these factors plays a vital role for the improvement of child health status.

The health care practices regarding ADL related to personal hygiene were studied out of 61 CWDs only 40.98 % were found brushing teeth and most of them had tooth decay problem as described by Antoon and Tompkins, (2000) i.e., tooth decay was the most common tooth problem in children. Tooth decay, also known as dental caries and gum diseased were caused by plaque. Plaque is a thin film of saliva and food residue in which bacteria grow and it can be removed by brushing child's teeth regularly. Out of 61 CWDs, maximum 95.08 % used toilet for defecation. During study it was found that 75.40 % trimmed nails when long and dirty, 77.04 % found combing hair daily, 78.68 % found wearing clean clothes and only 3.27 % taking daily bath daily. The rest of CWDs who were not maintaining personal hygiene were due to lack of awareness, time and negligence by the parents and caretakers. Because of these reasons, CWDs were facing health problems such as diarrhea, fever, constipation, heart disease loss of appetite, weight loss, weakness, pneumonia etc.

Hand washing behavior with soap and clean water, before cooking eating food, after using latrines, before and after caring of child plays a vital role for prevention of health related problems. So, out of 61 CWDs and their parents, 31.14 % washed their hands with water only, minimum 24.59 % washed their hands before and after caring of child. According to Luby, (1998) improper behavior before eating food and after using latrine was the main cause for the infection of Typhoid fever.

The study on water drinking behavior and its effect on health status of CWDs showed that out of 61 CWDs, 39 found drinking water directly from the source without any treatment

and among them 58.97 % had found health related problems. The rest of 61 CWDs were found drinking water either by filtering boiling or using chlorinated water.

The environmental sanitation was studied by observing and asking parents and caretakers of CWDs. Due to lack of knowledge and proper disposal area, the waste products coming from CWDs house were thrown either in open field/ditches near by the house. There were 49.1 % who threw in these places and many insects such as housefly and mosquitoes were found roaming in the house of CWDs and 76.66 % had health problems. The study also found that those who used container for waste management were found to have health problem with 64.16 %. The CWDs family managed waste products throwing in the container sent by sub-metropolitan city of Lalitpur district.

Rehabilitation is one of the important things that lead the life of PWD to a success. Only 13.5 % disable in the study area were getting rehabilitation services, the majority 86.5 % were not getting the services according to the field study done by Patan CBR, (2006). The present study showed that out of 61 CWDs 33 (54.09 %) were getting regular rehabilitation services and among them 25(75.75 %) CWDs were observed improving in their ADL related to health status. Those who followed the instructions and activities given by the Patan CBRO were 45(73.77) and among them 30(66.66 %) were found improvement in ADL related to health status. The present study also showed the positive effect on the health problems such as epilepsy, tooth decay and others such as fever, diarrhea, common cold, constipation etc. Dahal, (2000) studied and mentioned that institutionalized rehabilitation is very much needed for the severely handicapped who were completely dependent for other people.

The case fatality rate (C.F.R) was found to be 1.63 % as one of the CWDs of 16 years old male died due to severe bed sore and multiple problems such as physical and mental during the study. The cause for severe bed sore was lack of personal cleanliness, proper care of the wounds in time.

The result of the present study showed that among 15 respondents including staffs, caretakers and teachers, the preventive health services programs are run by Patan CBRO. According to them the programs were general health camps, awareness program on disability vaccination and nutrition. The promotive health services were promotion of inclusive education including health sector, budget allocation, promotion of disability rights and child club. The curative health services were providing medicines for epilepsy

to CWDs. The drugs preferred were Sodium Valproate, Valparin oral solution, Phenobarbiton, Vaveran (Diclofenac Sodium Tablets IP) etc. These drugs were given as prescribed by the doctors. The CBRO provided referral services to the CWDs by referring them to hospitals, health posts and clinics. The most important services given were rehabilitative services were physiotherapy, teaching ADL skills, providing assistive devices, counseling, exposure visit etc. The respondents had the views that the rehabilitative services would improve the health status directly and indirectly as they would be able to do health care practices by themselves.

VII

RECOMMENDATIONS

- The present study was focused only in 61 children with physical, mental and multiple disabilities visiting Patan CBRO of Lalitpur district because of fund and time limitation. For better understanding about health status of CWDs other rehabilitation center should be included and in large population.
- It is important to raise awareness about disability, that even though it may not be curable. The difficulties associated with it can be reduced to some extent and the condition may be improved with rehabilitation measures including preventive health measures. This would increase health care practices of CWDs in proper condition.
- The root causes of disability like diseases and accidents were reported in many CWDs. So, it indicates an urgent need to address preventive measures for disability in health sector.
- The rehabilitation services provided for CWDs lack proper health services i.e., not much focused on personal hygiene and sanitation. Thus, it is highly recommended that the existing health services should be improved and reinforced with referral services and well trained caretakers and staffs.
- Parents should immunize their children with B.C.G, D.P.T, Polio, Measles and Hepatitis B.
- Clean and safe drinking water and nutritious food with balanced diet should be provided in order to decrease malnutrition problem.
- Regular cleanliness of teeth and mouth is recommended in order to decrease tooth decay problem and plaque.
- Plenty of fluids, fruits and vegetables should be included in diet in order to reduce constipation.
- All CWDs should be trained in their basic activities of daily life related to personal hygiene and sanitation as far as possible so that they could be involved in daily living activities and maintain their health status by themselves.
- Regular health checkups and treatment of the diseases and illnesses should be done as prescribed by doctors.

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Annex- 1

Questionnaires

I. Survey on children with Disability

S.N.

- Name of the child: _____ Age/sex: _____ Date: _____
- Father's Name: _____ Occupation: _____
- Mother's Name: _____ Occupation: _____
- Permanent Address: _____
- Temporary Address: _____
- Types of Disability: _____
- Name of Disability case: _____
- Severity of the problem: mild () moderate () severe ()
profound ()
- Education: Illiterate () Primary Education () Lower secondary
Education () Secondary Education () Special Education ()
- Socioeconomic condition:
Source of income: Business () agriculture () Service ()
- Immunization: BCG () DPT () Polio () Measles ()
- Food type: veg. () Non-veg. ()
- Source of water: Tap () Well () River () Market ()
Government Supply ()
- Drinking Water: Boiled () Filtered () Both () Chlorinated ()
None ()
- Clothes: Clean () Dirty ()
- Brushing Teeth Daily: Yes () No ()
- Trimming Nails Timely: Yes () No ()
- Combing Hair Daily: Yes () No ()
- Bathing: Once a week () Daily () others.....
- Faeces and Urine disposal: Toilet () Outside the house ()
- Waste Management: Container () Near by the house () Other
places.....
- Washing Hands:
 - a. With soap and water ()
 - b. Before and after taking care of the child ()
 - c. After going to the latrines ()
 - d. Before cooking or eating food ()
- How the child becomes disabled? Congenital () Acquired ()

- Does the child have any other Diseases or health problems? Yes () No ()
If yes what are they?
- Treatment or Drugs preferred: Yes () No ()
If yes, List of Drugs:
- How often do you visit the Child in Rehabilitation Centre?
Regular () Occasional () Irregular ()
- Do you follow the instructions and activities to your Child given by the Day Care Rehabilitation Centre? Yes () No ()
- Changes found in the children after involving in Rehabilitation centre:
Improving () Constant () No change ()

II. Survey on C.B.R workers (Caretakers, teachers, staffs and others)

S. No.

Date:

- Name of the center/organization:
- Types of organization: NGO () INGO ()
- What are the funding agencies for the organization?
Government () INGO () Local CBOs (Community Based organizations) () others
- Which type of children with Disability does the organization have?
A) Physical Disability (No.):
Polio Paralysis () Cerebral palsy () Amputated () Leprosy ()
Muscular Dystrophy () Permanent problem of joint and spine ()
Club foot () Rickets () Problems of bone ()
B) Seeing Disability: Blind () Low Vision ()
C) Hearing Disability: Deaf () Hard of Hearing ()
D) Deaf Blind ()
E) Speech Disability ()
F) Mental Disability:
Intellectual Disability/Mental Retardation () Mental Illness ()
Autism ()
G) Multiple Disability ()
- Have you provided rehabilitation services to all the children with disabilities mentioned above?
Yes () No ()
- If yes, what kinds of services are provided for them?
Physiotherapy () Speech therapy () Occupational therapy ()
Braille () Sign language () Medicines () Total communication ()

- Referral services (Medical intervention, operation, assistive devices) ()
- Activities of Daily Life (ADL) Based Training ()
- Do you provide these things for the children free of cost? Food () Hostel ()
Clothes ()
- What kind of special services do you provide for Children with Multiple Disability?
- How often Day Care Center is cleaned? Daily () Once a week ()
Once a month ()
- How is the room environment of Day Care Center? Large/Open () Well ventilated ()
Bright/Sufficient Sunlight ()
- How is drinking water being used for the children? Boiled ()
Filtered () Both () Chlorinated () None ()
- Do you provide Tiffin for them? Yes () No ()
- If yes, what type of food do you provide usually?
- One type of food () various types of food ()
- Do you have referral services for the children? Yes () No ()
- What type of education is being enrolled for the children? Normal/Formal ()
Informal () Special () Inclusive () Integrated ()
- Do you provide assistive devices for the children? Yes () No ()
- If yes, what type of assistive devices?
Orthosis (Upper limb, Lower limb, Neck, Knee)
- Prosthesis (Upper limb, Lower limb)
- Mobility aids (Parallel Bar, Walker, Crutches, Canes, Wheel chair)
.....
- Positioning and posture supporting aids
- Hearing aids () Eye glasses () others.....
- Do you run any health awareness programs? Yes () No ()
- What type of health services programs do you run?
Preventive
- Promotive
- Curative
- Rehabilitative

Annex- 2

Significance test between different age groups and effect on health status of CWDs

**Table No. I. Results of age wise distribution of CWDs
(With health problem and without health problem)**

Age group	With H.P	Without H.P	Total CWDs
0-6	2	2	4
7-12	19	6	25
13-18	23	9	32
Total	44	17	61

Null hypothesis (H_0): There is no significance difference between different age groups and effect on health status.

Alternative hypothesis (H_1): There is significance difference between different age groups and effect on health status.

Calculation:-

S.N	Observed frequency(O)	Expected frequency(E)	(O-E)	(O-E) ²	(O-E) ² /E
1	2	2.88	-0.88	0.77	0.26
2	19	18.03	0.97	0.94	0.05
3	23	23.08	-0.08	0.006	0.00
4	2	1.11	0.89	0.79	0.71
5	6	6.96	-0.96	0.92	0.13
6	9	8.91	0.09	0.009	0.00
	Total				$\sum(O-E)^2/E=1.15$

Thus, the computed value of $\chi^2 = 1.15$.

The above table contains 3 rows and 2 columns; it is a 3×2 contingency table. For such contingency table, the degree of freedom (d.f.) = (c-1) × (r-1) = (3-1) × (2-1) = 2×1 = 2d.f. The tabulated value of χ^2 with 2 d.f. at 95% confidence level is 5.99. Since the calculated χ^2 i.e., 1.15 is less than the tabulated χ^2 at 95% confidence level for 2 d.f. i.e., 5.99, the null hypothesis is accepted which means that there is no significance difference between different age groups and effect on health status of CWDs.

Annex- 3

Significance test between gender and effect on health status of CWDs

Table No. II. Results of gender wise distribution of CWDs

(With health problem and without health problem)

Gender	With H.P	Without H.P	Total CWDs
Male	24	13	37
Female	20	4	24
Total	44	17	61

Null hypothesis (H_0): The gender and the effect on health status of CWDs are not associated.

Alternative hypothesis (H_1): The gender and the effect on health status of CWDs are associated.

Calculation:-

S.N	Observed frequency(O)	Expected frequency(E)	(O-E)	(O-E) ²	(O-E) ² /E
1	24	26.68	-2.68	7.18	0.26
2	20	17.31	2.69	7.23	0.41
3	13	10.31	2.69	7.23	0.70
4	4	6.68	-2.68	7.18	1.07
Total					$\sum(O-E)^2/E=2.44$

Hence, the computed χ^2 is 2.44.

From above table, the degree of freedom (d.f.) = (c-1) \times (r-1) = 1

The tabulated value of χ^2 at 95% confidence level for 1 d.f. is 3.84.

Since the calculated χ^2 i.e., 2.44 is less than the tabulated χ^2 at 95% confidence level for 1 d.f. i.e., 3.84, it is insignificant and the null hypothesis is accepted which means that the gender and the effect on health status of CWDs are not associated.

Annex- 4

Significance test between food taking habit and health status of CWDs

Table No. III. Results of the types of food taken by CWDs

(Nourished and malnourished CWDs)

Food type	Nutrition		Total CWDs
	Nourished	Malnourished	
Veg.	42	6	48
Non veg.	7	6	13
Total	49	12	61

Null hypothesis (H₀): There is no significance difference between food taking habit and its effect on nutrition.

Alternative hypothesis (H₁): There is significance difference between food taking habit and its effect on nutrition.

Calculation:-

S.N	Observed frequency(O)	Expected frequency(E)	(O-E)	(O-E) ²	(O-E) ² /E
1	42	38.55	3.45	11.90	0.30
2	7	10.44	-3.44	11.83	1.13
3	6	9.44	-3.44	11.83	1.25
4	6	2.55	3.45	11.90	4.66
Total					$\sum(O-E)^2/E=7.34$

The computed value of $\chi^2 = 7.34$.

From the above table, the degree of freedom (d.f.) = (c-1) × (r-1) = (2-1) × (2-1) = 1.

The tabulated value of χ^2 with 1 d.f. at 95% confidence level is 3.84. Since the calculated χ^2 i.e., 7.34 is greater than the tabulated χ^2 at 95% confidence level for 1 d.f. i.e., 3.84, it is significant and the alternative hypothesis is accepted which means that there is significance difference between food taking habit and its effect on nutrition of CWDs.