Disability and Rehabilitation:
An Ethnography of the
"Center for the Rehabilitation of the Paralyzed"
in Bangladesh

by Farjina Malek

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DECLARATION

For submission to the Examination Committee

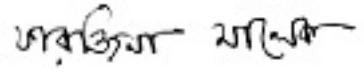
Regarding my Master's Thesis with the title:

Disability and Rehabilitation: An Ethnography of the 'Center for the Rehabilitation of the Paralyzed' in Bangladesh.

I declare that

1) it is the result of independent investigation
2) it has not been currently nor previously submitted for any other degree,
3) I haven't used other sources as the ones mentioned in the bibliography. Where my work is indebted to the work of others, I have made acknowledgement.

Heidelberg, 26.02.10



(Candidate's signature)

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Abstract:

In my research, I engaged in an ethnographic study at the Center for the Rehabilitation of the Paralyzed (CRP), Bangladesh, where the daily life of the disabled people and their experiences of their situation was my main focus. I evaluated their physical and mental situation by the language used by the patients, their relatives and the therapists and staff at CRP. Here language refers the representation of the physical condition (what is the synonyms and antonyms they use to indicate disabilities), and the way that patients, relative and doctors relate disability both formally and informally. My research question is 'what is the cultural shape of disability at half way hostel of CRP'? CRP is a huge area to cover, I therefore have chosen one part of CRP and that is the 'Half Way Hostel'. This is the patients' pre-discharged hostel. As a data collection technique, I used participant observation. I got myself involved in their daily activities. I took part as well as observed their daily life. In addition, I took interviews and daily notes. The thesis is divided in five chapters; the first chapter's aims were to introduce the argument, research question and then discuss different relevant literature. My argument is 'each and every culture has its own way of understanding disability. One should not consider disability from the universal point of view'. From this argument, my research question is, 'what is the cultural shape of disability at half way hostel of CRP, Bangladesh?' In the same chapter, I have also discussed how disability has been discussed in different time and literature. The second chapter is based on the description of the field and the data collection methods. In this chapter, I described my field; mainly the physical infrastructure of CRP, I discussed the method I have used as well as the limitations and advantage of those methods and I discussed my field experiences. As a volunteer, I got an easy access to my field; which was a plus point. On the other hand, for the same reason, my informants always kept a distance with me. It was a challenge for me to overcome the distance. The third chapter has focused on different events in CRP. These events have taken place at half way hostel in different time where the fun, frustration, every day conflict, love and joy of disabled people and their relatives is pictured. This chapter also focused some patients' case study, which is

helpful to understand the events as well as the patients' background. My forth chapter is the description of deferent points, where the holistic scenario of disability in half way hostel has been described. Apart of the patients, the other actors of half way hostel are more focused in this chapter. These other actors are the relatives of the patients, the discussants of the half way hostel, the therapists, the care giver of half way hostel and the other facilitator of the half way hostel. The concluding chapter of this study is based on the discussion of the study. The main findings of the study is the conflicts of CRP's advocacy and patients' own agency, the fun and frustration of the patients, the daily reaction of the relatives of the patients and also patients' everyday language. By the whole study, I have shown a culture of half way hostel, where disability plays a very influential role.

1.0 Introduction:

The '*Disability and Rehabilitation: WHO Action Plan 2006-2011'* notes that 10% of the total world population is physically disabled (WHO 2005: 1). Most of the literatures published by development organizations who work with the disabled quote similar values. There has recently been established an international convention regarding the human rights of people with disabilities. These two topics - the generalization of disability concept and the universal rights of disabled people, despite the differences in socio-economic conditions - motivated me to study the different cultural shape of disability and associated rehabilitation. My argument is that every disability has its own cultural shape. Moreover in a culture the disability may get different shape with the influences of age, gender, economic situation, and so on. To prove my argument in my research, I concentrated on, how disability gets its own shape in a small scale situation like half way hostel[1] of CRP[2]. From this perspective, my research question is: 'What is the cultural shape of disability at half way hostel of CRP? And how the different actors act to construct this cultural shape?' The subjects of my research, whom I refer to as actors, are comprised of CRP patients, the relatives of patients, the doctors, nurses, and other staff who work at the CRP, and others who are either in direct or indirect contact with the CRP.

1.1 Research Objectives:

The cultural shape of disability at the CRP is the central focus of my research. In this context, I want to know how disability is encountered by different actors at the half way hostel of CRP. This research is focused on the understanding of how patients, therapists, workers, and relatives of patients at the CRP interact with the

[1] After getting treatment patients used to stay in half way hostel for two weeks. Here patients learn to take therapy independently; they learn how to cope with their community in a new physical condition.

[2] CRP is a national NGO of Bangladesh founded in 1979. This NGO is focused on spinal cord injured patients. CRP treats the patients as well as works for their rehabilitation in the community.

greater society and among themselves, as well as the role that disability and rehabilitation plays in their daily lives. In order to address my central research question, I investigated several sub questions:

- What is the daily routine of a disable person and his care giver at the half way hostel of CRP?
- How do the patients relate their physical condition by their verbal language as well as their body languages both in formal discussion and in informal discussion or chatting.
- How do the relatives of the patients describe the patient's situation?
- What are the differences among those disabled based on their gender, age and economic condition?

1.2 Preliminary Work on the Research Topic:

My first university[3] is about 3 kilometers away from CRP. I personally first sought assistance from the CRP for back pain in 2003. As an outpatient, I had to go there several times. There were many things that interested me about the organization. First of all, they have many workers there who are physically disabled themselves, especially the people who work at the cash counter. Later, I found a shop in the CRP compound where they sell many crafts made by the disabled in-patients. The goods of the shop really impressed me, and I wanted to know about their makers; I came to know that most of them live in the compound. As an out-patient, I knew only a small area of the much larger ground. I returned to CRP in 2006 for a severe problem with my leg (I fell down and suffered a torn ligament). I came regularly to the CRP for several days and I came to know some of the patients more closely in this time. I became interested in their lives, their perceptions of their bodily constitutions, and so on.

[3] My first university is Jahangirnagar University, which is in Savar, Dhaka. I did my bachelor and masters degree in 'Geography and Environment' in that university. That is why, I stayed there for 6 years from 2002 to 2008.

In 2008, I came to Heidelberg for my MA in Medical Anthropology. As a part of our study, we visited various UN organizations in Geneva, Switzerland in April, 2009. Autonomously, I sought out Handicap International and spoke with a few members of that organization. I also went to the CBR (Community Based Rehabilitation) Project of the WHO. This study excursion increased my interest in the lay perspective of disability because I found the agendas and work policies of these two organizations to be very grounded in universality. These organizations function holistically on a single concept of disability for all different cultures and apply the same policies for disabled people all over the world. There is not even a differentiation in prescribed rehabilitation process for different cultures. I am very interested in how a universal idea can work in a local setting. To meet my interest, I sifted through different kinds of literature, to include books, articles and many reports of the organizations who work with disability issues. This literature review is a fundamental part of my preliminary work for my field research.

1.3 Literature review and the rationalization of the study:

My research is focused on how the concepts of disability are encountered in different contexts, both of which need defining the terms. Defining 'disability' is problem because of its intricacy and multidimensionality. As a result, a global definition of disability that fits all contexts, though desirable, is nearly impossible in reality (Slater et al. 1974). Both scholars and different (national and international) organizations try to define disability with simple statements, theoretical models, classification schemes, and even through different forms of measurements. Altman observed that ''there is no neutral language with which to discuss disability, and yet the tainted language itself and the categories used influence the definition of the problem" (Altman 2000:97). He also argues that defining disability has ''contributed to the confusion and misuse of disability terms and definitions, particularly when operationalized measures of disabilities are interpreted and used as definitions" (Altman 2000: 96). However, the concept

of disability covers its definitions, the role of the 'experts' (leaders in different organizations who are working with disabled people), the place of experience, and the nature of local politics at that time. Altman argues that ''when trying to make sense of this variety of ideas and forms, it is necessary to take consideration the structure, orientation, and source of the definition" (Altman 2000: 96). Therefore, clarifying the variety of definitions, analyzing their sources and understanding their conceptual strengths and weaknesses in different contexts are the three objectives of my literature review.

There are four basic historical categories of attributes toward disability: the individual model of disability, the environmental model of disability, the social model of disability, and the model of the interaction between the individual and social concepts of disability. In the individual model, disability was systematically identified as a characteristic of the individual person (Fougeyrollas and Beauregard 2000). Due to the functional difference of his body, it was the responsibility of that person to overcome any obstacle that he encountered. Any person with significant impairment was labeled handicapped or disabled, resulting in social exclusion and stigmatization. This conception of disability has progressively changed since the 1960s, when several people questioned this reductionist representation of disability; these voices led to the emergence of the disability rights movement (Fougeyrollas and Beauregard 2000).

Despite much advancement, there is no consensus as to the determining factors of disability, notably with regard to the environment (the second model), even today. In fact, it would be more accurate to say that there is consensus on the importance of the environment but disagreement on the exact role that factor plays. On the one hand, there is a social model that attributes disability entirely to the environment, ignoring the factors related to the person. On the other hand, there is the biomedical model that mainly focuses on the person and resists consideration of environmental factors. This resistance is notably manifested within the scope of the ICIDH-1 (International Classification of Impairment, Disabilities, and Handicaps) published by the WHO (World Health Organization)

in 1980. The ICIDH-1 conceptual framework is based on the trilogy of body, person, and society (WHO, 1980). The ICIDH-1 model presents a cause-effect relationship between impairment, disability, and handicap. In this model, disease or disorder is shown as intrinsic and *causing* of impairment, which ultimately results in disability. Finally, both disability and impairment can be causes of handicaps. In the social model, impairment is considered to be an 'exteriorized' situation, disability is an 'objectified' situation, and handicap is a 'social' situation. Thus, an injury that leads to the impairment of an organ's functions and structures, which then leads to a disability in the person's behavior and activities, ultimately generates one or many handicaps or disadvantages concerning social or survival roles.

Since the dissemination of the ICIDH and its experiment application within diverse fields of study, the problems identified, the critiques, and the adaptation to the conceptual model and classification manual have stimulated for the search for knowledge: "the most passionate debate is related to the critique of the linearity of the ICIDH model and the work that attempt to explicitly introduce the systematic approach and environmental dimension into the conceptual model" (Fougeyrollas and Beauregard 2000: 176). The modifications brought forth by these emergent conceptual models aim to illustrate the person-environment relationship in the construction or prevention of 'handicap'.

Thus in 1992, Minaire proposed his concept of the 'situational handicap', defined as the result of the confrontation between the functional disability presented by an individual and the situation encountered in daily life (Minaire 1992). In that time, he published an improved version of the conceptual model, explicitly integrating diverse categories of environmental aspects analyzed in terms of situation. According to Minaire (1992), environmental aspects are both social and physical dimensions that determine a society's organizations and context. In physical factors, he mentioned nature and the development of a society. Here, nature is defined as the physical geography, climate, time, sound, etc., and development is manifested in the architecture, technology, and national and regional

advancement. Minaire (1992) also broke social factors into in two parts: one is the politico-economic factors and socio-cultural factors. Politico-economic factors are comprised of government systems, judicial systems, economic systems, health systems, etc., and socio-cultural systems mean social rules, norms, and social networks. Minaire (1992) specified that one is handicapped not in the absolute but with the reference to something. In his opinion, the situational handicaps model completes the dimensions of the WHO model by integrating the person within his/her environment (Minaire 1992). Thus, a handicap is a characteristic not of the person but of the interaction between the person and his environment. In this way, Minaire refutes the linearity of the WHO classification. Following Minaire, several authors: notably Badley (1987), Chamie (1989), and Hamonet (1990) elaborated upon conceptual models that integrated the concept of environment as a determining factor in the disablement process.

The ICIDH-1 was published during a period that also a witnessed the International Year of Disabled Persons, (proclaimed in 1981 by the United Nations) and the Decade of Disabled Persons, which ended in 1992. This period was characterized be the preparation, adoption and application of policies and legislative measures aiming to promote and ensure the exercise of the rights of disabled people (UN 1983). Despite its innovative conception at the beginning of the 1970s, with the introduction of the social concepts of handicap to the biomedically oriented WHO, the ICIDH and its conceptual framework failed to become the international reference tool for persons with disabilities (Barry 1989).

A worldwide disability movement, Disabled People's International (DPI), rejected the ICIDH-1 definitions in 1981 and adopted definitions that are known as those of the 'Social Model of Disability' (Oliver 1996). According to this model, disability is exclusively caused by the presence of barriers within the environment and occurs because the environment does not succeed in adapting to the needs of people who have certain impairments. To improve the life situation of the people with disabilities, one must remove the environmental factors that create obstacles to their integration; the model pays little interest to their organic and functional

differences (Enns 1989; Hurst 1993). The DPI defines impairment and disability as follows:

"Impairment is the functional limitation with the individual caused by physical, mental and sensory impairment. Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (DPI 1982: 3).

Within a political paradigm, the social model has insisted that there is no causal relationship between disability and impairment. The achievement of the disability movement has been to break the link between bodies and social situations and to focus on the real cause of disability: Discrimination and prejudice (Shakespeare and Watson 1997). The concept of equalization of opportunities, meaning the process by which society is modified to become accessible for people with disabilities, is putting the social model into action; it was first used in a United Nations document, *Decade of Disabled Persons 1983-1992: World Program of Action Concerning Disabled Persons* (UN 1983). These radical changes in the early 1980s were largely the result of a partnership between the disability movement and various governments (e.g. Canada and Sweden), who adopted the new principle of participation. This new outlook of disability has influenced the development of legislation like The Charter of Rights and Freedoms in Canada and The Americans with Disabilities Act (Enns 1998: xii).

From this perspective, disability is a political issue. Disability right activists consider that the social environment structurally creates social disadvantages and discriminatory situations experienced by people with disabilities (Driedger 1989; Hahn 1985). Disability is socially constructed and manifested in situations experienced by environmental barriers and causality is no longer placed within the body and functional limitations but in the systemic inadequacy to adapt to their specific needs and oppression (Oliver 1990). It is important to note that the adoption and application of social policies and legislation ensuring the rights of the basic human rights and equal opportunities constitute modifications of the

environment that have had an obvious impact on the disability and rehabilitation process. The impossibility of monitoring the evolution and impact of these factors through biomedical and compensation models is centered on an inside-the-individual model of disability. This fact has led numerous government planners and decision-makers to support the movement for the defense of human rights in the critique of the ICIDH and the inclusion of environmental variables for monitoring and measuring the impact of socio-economic policies in the field of rehabilitation, de-institutionalization, and social participation. This change is well-exemplified within the UN standards for the equalization of persons with disabilities (Barry 1995).

Another major criticism of the ICIDH-1 was its lack of conceptual clarity and overlap between the concepts of impairments, disabilities, and handicaps (Nagi 1991). This oversight is mentioned by the Committee on a National Agenda for the Prevention of Disabilities in its report, "Disability in America," in order to explain the rejection of the ICIDH as a conceptual framework. The committee preferred the concept used by Nagi (1991), wherein the disabling process is made up of four elements: Pathology, impairment, functional limitations, and disability (Pope an Tarlov 1991).

After much criticism, WHO changed the ICIDH-1 model. The introduction of the ICIDH-2 states that, "The overall aim to the ICIDH-2 classification is to provide a unified and standard language and framework for the description of human functioning and disability as an important component of health" (WHO 1999: 7). The classification covers "any disturbance in terms of functional states associated with health conditions at body, individual and social levels" (WHO 1999: 7). The new draft of the ICIDH-2 proposes three dimensions of the concept of disability: body functions and structure, activities in the individual level, and the participation of the individual in society; it also includes a list of environmental factors. The title of the classification has been changed to ICIDH-2 International Classification of Functioning and Disability ('functioning' and 'disability' are defined as umbrella terms).

This final conceptual scheme shows that the individual's health condition (disorder or disease) depends on the aforementioned three basic concepts, which are inter-related themselves. These inter-relations again depend on the environmental factors and one's personal orientation. The body thus has a role in disability at any level of human life (Fougeyrollas and Beauregard 2000).

The ICIDH-2 was the result of various influences. It indicates positive change because it recognizes disability within various contexts and cites socio-political and environmental models as essential for counterbalancing the biomedical and economic model based on solely the individual (Bickenbach 1993). Here, the importance of environmental factors are recognized, but there is resistance to making this a separate and full fourth conceptual dimension. The systematic nature of disability phenomenon is acknowledged, but the explanation is made even more confusing by the proposal of a complex conceptual framework that fails to clearly identify the interaction between the individual and the environment as a central factor. The importance of the individual was recognized, but as an unclear contextual factor, creating some confusion with regard to environmental factors (Fougeyrollas and Beauregard 2000).

In 2006, Tom Shakespeare published his book entitled '*Disability Right and Wrong*', wherein he critiqued the ICIDH-2 social model. He thinks that, ''[social model] approaches reject an individualist understanding of disability, and to different extents locate the disabled person in a broader context" (Shakespeare 2006: 9). This social model has also been counterposed to the medical model, a limitation of the former. Shakespeare (2006) stresses three points in order to understand disability and the rehabilitation processes of disability: Social and environmental barriers, the individual concept and sufferings, and the medicalization of disability. To understand the perception of disability and rehabilitation of a particular area, it is important to know the local culture and social settings, the disabled person's concepts, the treatment procedure for disabled person, and the political systems regarding disabled.

In this context of disability study, I want to focus on a particular institution, which is working with disability. I want to examine their understanding about disability and review this understanding with the aforementioned models. However, in my research, I do not take disability as a universally define phenomena, rather the local cultural understandings of disability is important. Therefore, this research is to compare the different models to CRP's experiences of disability, arguing that culture plays a role to construct the idea of disability.

1.4 Chapter plan of the study:

This chapter describes the overall idea of the study. The argument of the study is 'every disability has its own cultural shape'. To prove this argument this research selected a small scale area name 'half way hostel' the pre-discharged hostel of CRP, Bangladesh. After getting treatment patient come and stay in half way hostel for two weeks to learn therapy and other works, those are important and appropriate for their physical condition. They create a temporary territory there, which have a unique cultural shape. This study is an ethnographic description of that culture, where the disability plays a vital role to give a shape of that culture.

Apart of this chapter, this study has four more chapters. The second chapter is focused on the description of field and methodology. I collected information by observing and participating in the daily life of half way hostel, which is my field. This chapter is a description of the experience of entering to the field, the advantage and limitation of my field. At the same time, this chapter conveys the gap within the planned methodology (what was in my mind before going to the field) and the methods, what I used in my field.

Third chapter is based on the daily events at my field. The aim of this chapter is to get the picture of the culture of half way hostel through the daily life activities. The argument of this chapter is, with the influences of different kind of people; like patients, relatives, doctors, and therapists, half way hostel got a unique

culture. Moreover, this unique culture is always changing due to the age, gander, and socio-economic variation of these actors.

The forth chapter is more focused on the particular issues in half way hostel; for instance, discussion that take place there, type of care giver of the patients, outing and gardening for the patients and so on. The aim of this chapter is to show the contradiction between CRP's discipline and patients' self agency.

Finally the fifth chapter is the conclusion of the study. This chapter has drawn the conclusion by showing the contradiction between different models of disability and the scenario of disability at half way hostel.

Chapter Two: Data Sources and Data Collection Methods

2.0 Introduction:

In my methodology section, I will first describe my field, which will not only cover the geographical location of my field, but also my informant types, the events that take place in my field, and my experience to enter the field. Then, I will discuss which methods I used to collect the necessary data, the sample size & time frame. At last I will stress on my ethical position at the field.

2.1 My field:

I knew CRP before as a patient[1]. CRP has its several centers for treating and rehabilitating of paralyzed patients in Bangladesh. CRP's headquarters are in Savar, approximately 25km far from Dhaka, the capital city of Bangladesh. This headquarter was my field. There are several buildings and facilities in that compound (100-bed hospital, Operation theatre, Physiotherapy Department for in-patients and out-patients, halfway hostel where patients prepare for returning to their home communities, vocational training centers, etc.). I had a limited idea of CRP from my past visits at CRP and CRP's website. However, when I went to CRP for my field work, I was checked by the security. They asked me, where I wanted to go. 'I want to meet with Mizan Vai (Mizanur Rahman is the volunteer coordinator of CRP)' I replied. Security asked quickly, 'which Mizan? Wheelchair-Mizan? Or Crutch Mizan?' It was clear to me that both of the Mizans are disabled. I replied that I was looking for the volunteer coordinator and I did not see him before. Two guards discussed together and suggested me to go to BHPI (Bangladesh Health Professionals Institute) building to find out

[1] I have been living in Jahangir Nagar University campus from 2002 to 2008 for my bachelor and masters. This university is about 3km far away from CRP. I first went CRP for my back pain in 2003. I had to go several time there for that reason.

'wheelchair-Mizan'. I passed the gate and then the out-patients area. There were around 25 out-patients in that big hall room. The two side of that hall room were open and other two sides were closed by the Doctors room. I saw one young girl was howling in pain. She fall down from the tree just an hour ago and got hurt in the back. Her father was busy to fill up the appointment form and they are waiting for the doctor. I passed them to meet with Mizan Vai. I went to the Speech and Language Therapy Department in BHPI. Mizan Vai is the lecturer of that department and the volunteer coordinator of CRP. He told me that CRP offers nine courses in BHPI; bachelor degree In Physiotherapy, Occupational Therapy, Speech and Language Therapy, Nursing Diploma and also some other diploma and assistance courses. There is no ramp in BHPI building; however Mizan Vai has the ability to use the stairs with his hands and knees. He got another wheelchair in the ground floor. We went together to the main administrative building to fill up my volunteer form. The administrative building was situated directly opposite to the BHPI building. In the main administrative area, we got a ramp. I filled up the form and then we moved around CRP; the In-patients area, the clinical physiotherapy, occupational therapy and speech & language therapy department, half way hostel, vocational training centre, staff quarter, inclusive school and the big hall room name Redda Way Hall. For my field work, I choose the half way hostel. I knew the concept of half way hostel before from the website of CRP. I showed my interest to work there. I got an introduction of half way hostel and started to work there. There were twenty beds for the patients, one office room, three toilets, one tube-well, one office room and one hall room in the half way hostel. Three permanent staff work there; a physiotherapist, an occupational therapist and a caretaker. Most of the other works are done by the other staff of CRP; for instance, in discussion period one councilor come and then goes back to his own work or in individual therapy's time one or two physiotherapists come and after the session they go back to their previous work. Patients come in the half way hostel after getting treatment as in-patients. The concept of half way hostel is to make patients more independent. Patients learn here how to take therapy, how to cope off with their old environment, how to do daily work more independently. This hostel runs by its

daily routine. Every day from 8 am to 8.50 am they have group therapy. The patients and the therapists select a group leader from the patients. The leader has to know the therapy. They have Physiotherapy for every parts of the body. After 10 minutes break, discussant from different departments like social welfare or vocational training institute, come and discuss with the patients on three days in a week. In every Saturday, the patients got the idea of half way hostel and the other three days (Sunday, Tuesday and Thursday) they discuss on various topics, such as hygiene, pressure sore, the home environment, use of wheelchair, future profession, and social relationship. Monday and Wednesday are days for gardening. Patients do gardening under the supervision of the staff of half way hostel. Though in rainy season, they have to pass their time inside the hall room. After one hour of discussion or gardening patients start to do the individual therapy. If any patient requires special kind of therapy they can learn that in this period. The care givers of the patients also learn how to give therapy in this time. At 12 pm patients go to the vocational training centre. CRP offer six types of vocational training; tailoring, computer training, electronics servicing, shop keeping, and painting training. In the half way hostel the most training is the shop keeping. A person without one leg and one hand runs this training. I did find this training is too much effective. I saw the trainees were dissatisfied with the training. I asked one trainee, who is a member of half way hostel about the training. He told me 'look sister, I have to laugh with the customer and I will be well-mannered to them; this is not a matter of learning rather this is a matter of common sense.' I got only four patients out of twenty who were regular in the vocational training on that particular time. The patients, who don't attend in the vocational training, have to go to the Redda way hall of CRP. Every day from 12pm to 1pm, patients work to produce the package and the bandage for CRP's internal necessities. Then, they get the launch break for one and half hour. They come back at 2.30 pm from their break. In different days of the week, patients get different work on that time. On every Saturday there is a cultural program, In-door games on Sunday and Tuesday, film show on every Wednesday and Monday is for discussion. CRP has three selected film for the half way hostel's patients; Radio Vai (Radio brother), Bihongo (The birds) and Wheel Chair. All the

films are produced by CRP. After this cultural program session, patients go to the 'wheel chair skill' for half an hour. For this 'wheel chair skill' training CRP made an intricate ground. With Three trainer wheel chair users go through the ground. Before going back to the hostel, patients join in the outdoor sports for an hour.

As a volunteer, I maintained the office time of CRP. From Saturday to Wednesday, I had to stay in half way hostel from 8am to 5pm and on Thursday 8am to 1.30 pm. Very often I stayed after 5pm to collect more data in their chatting time.

2.2 Entering to the field:

I entered to my field as a volunteer. Many Anthropologists face the problem to enter to the field. Dr. Shahaduzzaman did his hospital ethnography in a Bangladeshi hospital (Zaman, 2005). He got a huge problem to omit his identity as a doctor. At the same time, he was not like a patient. As a result, in the beginning it was a challenge for him to gain the faith from his informants (Zaman, 2005). I did not have this kind of problem to enter in the field. CRP always recruits a good number of volunteers. Like the other volunteers, I did not get attention from the staff and patients. However, as a volunteer, I had to do many things which are not directly related to my research topic; for instance, maintaining the attendance of the patient's daily activities, counseling the patients, helping them in the extra curriculum activities and so on. In the beginning, I thought these duties are not relevant with my thesis. Later I discovered that irrelevant activities are very important to get a clear picture of my field. By doing these kind of works, I got a high status to the patients, in one hand which is good. I did not have any problem to collect the data; patients and their relatives were eager to give me information. On the other hand, they always behaved formally with me, which was a disadvantage for my field work. It took couple of days to break this formal relationship.

2.3 Data collection technique:

Participant observation was the fundamental method of my research: I was in the field as a volunteer for two months. I stayed in the CRP hostel, which is inside CRP premises. As a result I frequently visited half way hostel even after office time. I tried to participate in their daily life. However, the concept 'participant observation' broad itself; Singha (1993) mentioned four possible roles for a participant observer: 1) a complete participant, 2) participant as observer, 3) observer as participant 4) a complete observer. As a volunteer, I was not able to be a complete participant, as I could not completely involve myself in the daily lives of the patients. Thus, I will not be a complete observer either. My plan was to fall into the second and third categories: I was a participant as an observer and at the same time an observer as a participant. However, many anthropologists even doubt the term 'participant observation'. Geest and Sarkodie wrote that, "participant observation is not an easy thing to do, or to be more precise, it is impossible. Participant observation is a dream, an ideal, and a contradiction in term" (Geest and Sarkodie 1998: 1373). Therefore, I observed daily life at CRP through my work and through building an informal relationship with my informants on the site. I have used many different methods to collect the qualitative and quantitative data to supplement my participant observation.

For the convenience of data collection, I have divided the information into three categories: place (the half way hostel), people (the patients, staff and the relatives of the patients) and events (the daily life of the hostel). For the place part, I have collected both quantitative and qualitative data. With regard to the people, my focus was on the qualitative data gathered from the patients, their relatives and the people who work there. Here, I have used different tools; In-depth interviews, case studies, mind- map, observation, Semi- structured interviews, and conversation. For the third part of my data, I gathered primarily quantitative information on the daily schedules and events at CRP and then descriptive information on each and every event of half way hostel at CRP. The following tables and the explanation, shows detail of the

information or the data what I need for my research and which method I will use for collecting this information.

Table 1: the Place: Half Way Hostel

Place	**Types of information**	**Data collection methods**	**Potential informants/ sources of information**
CRP	Location and history of CRP, existing facilities, staff strength, number of patients, physical environment, building arrangement.	Observation, secondary source and semi-structured interview.	CRP library, staff of CRP, website of CRP, Local people
Half-way hostel	Number of rooms, room arrangement, existence facilities inside the hostel	Observation, conversations, secondary source.	Members and workers of halfway hostel, relatives of the member
Patients' access area	Vocational Training, outdoor sports, nursing service, social welfare unit's service	Observation, semi-structured and in-depth in interviews.	In-patients, relatives of in-patients, workers and therapist of CRP
Staff rooms	Facilities inside the room, the activities that take place in the rooms.	Observation, interviews.	Therapists, Workers, administrative officers

To get the information on my study place, I mainly used secondary sources. CRP's publications, website, documentaries on CRP were some of my secondary sources. Apart of these secondary sources, I took interview, observed the facilities and talked informally with all type of people at CRP.

Table-2: The people

People	**Types of information**	**Data collection tools**
Patients	Social background, daily activities and accessed area in CRP, communication with the staff, perception about their life, views about the center and the treatment,	In-depth interviews, case studies/ life histories, mind- map, observation
Doctors / Therapists	Activities of different doctors/ therapist, interaction with other staff members, interaction with the patients, perception of disability.	Observation, Semi-structured interviews, in-depth interviews, conversation
Staff (excluding doctors and therapists)	Activities of different staff; interaction with the other staff member, communication with the patients, perception about the patients	Observation, Semi-structured interviews, conversation,
Relatives of the patients	Relationships with the patients, perceptions about the disease of patient, experience that gathered for having disabled person in a family, interaction with the CRP's staff	Observation, case studies, in-depth interviews, conversation

Three kinds of people were my target; first- the patients. I wanted to know how they describe their physical and mental condition. I focused on their language. I tried to observe which words they use for their condition and which words for the opposite condition. I participated in their daily life; I observed their work and their participation in different work at half way hostel. I took 15 interviews to know details about them. I also used mind mapping to understand disabled peoples' daily accessed area. My plan was to provide them pen and papers and tell them to draw CRP. From their drawing, I thought I could find the accessed area of patients at CRP. The mind mapping idea was not useful for my field because most of the patients could not use the pen and some of them got paralysis in hand so they could not even move their hand. However, all the other methods I used were useful enough. My second target people were the employees, who work for those patients. Each patient evaluates his life with a special concentration, but the employees have to deal with many patients in a day. My interest was to know their feeling on disability; how they describe the condition of a disabled person. I observed them; we discussed together on different issues of the patients and we worked together for the patients. As a result, it was easy for me to get the data from the employees of half way hostel. My final target group was the relatives of the patients. The patients, who cannot move their hands and legs, have to bring their relatives. At the same time other patient's relatives very often come and rent a home outside CRP. They were also my informants. I talked to them, observed their reaction in the discussion, therapy and the other time. Very often, I participated on their evening gathering time. They discussed on different events of the following day, which was a very important source of my information.

Table 3: The Events

Events	**Types of information**	**Data collection tools**
Doctor's/ therapist's daily round in the half way hostel	Procedures, interaction	Observation
Admission and discharge of patients	Procedures, interactions	Observation
Discussion	Procedures, interactions	Observation
Dressing, distribution of medicine, washing and meals	Procedures, interactions	Observation and conversation
Sports, vocational training, gardening and the other extracurricular activities	Interactions and the participations of the patients	Observation and conversation

The information of different events was the most important part of my research. I attended in the regular events of the half way hostel. I saw the patient's participations in the event, their interaction with the event and their reaction on different matter of that event. In the leisure period, I often asked to the patients and their relatives on a particular event and observed their reaction. Observation and conversation were the main methods to collect the information on the events of half way hostel.

2.4 The limitation and the advantage of my field:

There is a metal and wood workshop behind the half way hostel. CRP makes its wheel chairs, special seats for the patients, and the other metal things in their own metal workshop. The noise of welding machine of that metal workshop made the workshop area and the half way hostel polluted. It was impossible for me to tape the voice inside

the half way hostel due to this noise pollution. Often I took my interview outside the half way hostel.

Another limitation of my field is that CRP works for the spinal cord injured patients. As a result, I got a particular type of disabled people there. It is indeed a limitation of my work. On the other hand, I could only focus on a specific type of informants. However these patients come at CRP just after their accident. That is why they could not imagine the loneliness of a disabled person in their local community. This is another limitation of my work. I got the informants, who are used to see too many disabled people around them at CRP.

Language played a vital role in my thesis. First of all, to understand my informant's daily speech, I needed to know the local dialect. Though my native language is Bengali, but some of the patients speak in hard dialect which is tough to understand. Moreover, to understand their jokes and silent language, I needed to understand the cultural context of those people. Then the problem rises with the data representation. Many things are easy to understand in Bengali and tough to translate and represent in English. Furthermore, there are many jokes, fun and frustration, which could be translated, but hard to realize the meaning because of the cultural gap.

I got many advantages in my field as well. First of all I got many disabled person at a time in one area, which is a big advantage for my fieldwork. Second thing was my residence at CRP's volunteer guest house. I could stay at half way hostel as long as I wanted as I did not have to worry about the distance between my workplace and residence. At the same time, I stayed there with twenty more volunteers. Many of them came for their study (like research, placement, and internship). I shared many things with them, and we discussed different issues, that discussions were very helpful for getting a clear understanding on the particular issue.

2.5 Sample size and time frame:

Before going to the field, I did not have any sample size as I wanted to do a participant observation. However after my field work I got a number of informants including their different quantitative information, which will be helpful to get an overall idea of those patients (Annex-1). I was in Half Way Hostel for two months (from 1st of August to 1st of October, 2009). During my field work period, I got 62 patients and 35 care giver in the half way hostel. Out of these 62 patients, only 10 were women. I have taken 15 in-depth interviews of the patients and had conversation with all of them. I had also 5 semi-structured interviews with the staff of CRP. Out of 5, three of them were therapists, 2 were assistant of the therapists.

2.6 Ethical considerations

I worked with the paralyzed patients at CRP. Naturally, they are more sophisticated than 'normal people' (according to biomedicine), as the greater part of the society discriminates them, even with regard to standard daily movement (lack of wheelchair accessibility to facilities, or in busses, trains, or cars), education (special schools for disabled people are only for secondary level), and jobs (lower education levels mean fewer job opportunities). In my research, ethical consideration is very important because I was working with their daily experience, daily feelings, and daily reaction with the existing facilities. I also worked with the rehabilitation process and its limitations or usefulness from the point of view of the patient. Here, I will be very careful to maintain confidentiality of their information, knowing that if the CRP authorities knew that the patient was dissatisfied and complaining, that result in consequences for the patient himself. I asked all of my informants about their preference for interview methods. I used my tape recorder with their explicit. Finally, I wanted to provide a written and signed statement of confidentiality that I would honor until they personally ratify its content. However, they all gave me the permission to write on their life and to mention their name.

2.7 Conclusion:

The focus of this chapter was to show the field and the data collection technique from the field. My field was half way hostel of CRP (Centre for the Rehabilitation of the Paralysed), Bangladesh. Half way hostel is one of the rehabilitation areas of CRP. Patients come to the half way hostel after completing their treatment from CRP. They stay usually two weeks there. I was in the half way hostel for two months. I participated in their daily life and observed their life. I collected the information by participant observation. To supplement this participant observation I have used many different methods like interviews, mind maps, case studies, and life histories.

Chapter Three: Daily Life in CRP; Living with Disability

3.0 Introduction

In my research question, I have noted that I want to know the cultural shape of disability. This cultural shape of disability can be understood from everyday life of disable person. Disable people express their situation to the care givers; care givers at the same time express their reactions. These reactions and responses are there in the everyday life of half way hostel, which are important to understand cultural shape of disability. In this chapter I will focus on this issue.

3.1 Expression of Pain:

'Oh God take me, take me (Allah, tui amare nia ja)' Ershad was shouting with this sentence. He was the only one patient in that hall room. Most of the patients went to the sports. His wife and me were sitting behind him. His wife is not too old but her face seems older and rude. There were two more patients few minutes ago; Khokon and Mofizur. I was playing chess with them; suddenly Ershad started to cry and his wife was a bit careless. Khokon vai told me 'look madam, how rude the wife is'. I asked, 'what happened?' 'Ershad peed in his lungi (lungi is like a skirt, but mostly the male of south Asia wear it), so his wife behaved rudely with him. Mofizur vai was leaving the room and saying himself, 'how bad women she is, no respect for husband…'. Khokon Vai react as

Ershad is a 24years young married man. His home town is in Tangail, which is about 100 km far from Dhaka. He was a farmer. One day he was carying a load of paddy tree. Suddenly he fell down in a rat hole. He got hurt in his neck. His bone in neck broke. Ershad was taken directly to the district hospital and that hospital referred him to CRP. According to the assessment of the therapists, he has to use wheel chair for ever. However, the topography of his area is not plain; the area is full of up and low land. He has a house in a high land and paddy field in a low land. The low land goes under water during the rainy season at least for four months. As a wheel chair person, movement is so difficult for him. Moreover, in the rainy season, it is impossible. On the other hand he took shop keeping training from CRP and wanted to give a shop in the market. When I asked whether it is possible to maintain a shop with this circumstance, he did not give any answer.

well 'my wife is 100 times better than this woman, I shout a lot, but she never reacts or behave rudely'. However, the wife of Ershad was careless like before. She was starting to do her task in a rude and quiet way; she changed Ershad's lungi, cleaned the body, and rubbed the lower part of the body. Aminul vai, the care taker of half way hostel came and tried to make her understand 'look don't misbehave with your husband, if God wants you might become disabled in a second, who knows what is going to happen with us!' The woman replied that they don't have fan in their room. Her husband could not sleep last night at all and make her awake and after a long sleepless night how could she control her temper. Aminul vai left the room and the women took a seat next to the patient. Then Ershad, the patient, started to cry again. He was splitting repeatedly. Feeling pain in the chest and could not take breath. Some patient's relatives came by this time; they were suggesting the women to go to the nursing station. The woman was trying to pick him up to the wheel chair, but failed. I hesitated to help her not only because he was dirty but also as a Bangladeshi female it is tough for me to take a man on my arm. There were no male around. At last with the help

Khokon Sharder (32): He is a very talkative man at half way hostel. Before accident, he was a line man of Polly Bitdut (A company for electricity supply). He had to climb electric poles for maintenance purpose. One day he falls from the electric pole and got hurt in back. He took the shop keeping training and wants to build a shop of electronic products back in home.

Mofizur Rahman (22): he was laying under his truck, checking its wheel, all of a sudden the truck started to move. A child had climbed up onto the truck, turned the key and got it moving towards his chest. Thus the truck driver Mozifur Rahman got his chest crushed. After having spent several months at the medical care division of CRP-Savar, Mozifur went back to his home in Khulna division to try to live the life in his wheelchair with his parents, sisters and brothers, wife and his four years old son. He would also try to find out ways to earn living for himself and his family. He would decide whether he would work as a shop keeper or earn money from renting out his parents property. He supposed to go back to his home after couple of weeks at CRP for his vocational training, but he did not leave even after three months.

of some other women, his wife picked up him on the wheel chair. Ershad was crying and shouting 'I am dying, I am dying, call my parents, my sister, I am dying.' They came back after 20 munities and then the wife was shouting 'look sister, all blamed me. Now see, he trough out the pill by vomit and again make dirty everything. I will die by cleaning and cleaning.' By shouting she was helping her husband to transfer him wheelchair to bed. The patient was shouting at the same time as well, 'take me to my home, I will die. Call my sister over phone. Tell them to take me home'. Slowly the patients and the therapists came back from the field. One therapist name Lockman asked Ershad, 'what happened to you?' He replied, 'Sir, please save my life. I am dying. My two legs are burning. Please give me some ice. Lokman vai heard all the events and said to Ershad, 'if I give you ice you will get a cold then, do you want this? This is very normal to have some pain in this time.' The other patients also voted in this regard. Heamayet Fakir, another patient, said 'you don't know how much pain I have tolerated every day. You have to adjust with it. Don't behave like a woman.' Ershad's wife came to me and whispered 'sister, he got a bad wind. When you get this type of bad wind, you have to suffer three times. Previously, he got injured two times and this is his last time. But this time his neck broke. I came here to treat this broken neck, but now we need to go back to kaviraj (traditional healer in Bangladesh, they mainly use the herbal medicine and very often they recite mantra for the patient's well being). The kaviraj will give him back the strength of his hands and legs'. I asked 'why three times of suffering? Why not more or less sufferings?' She replied 'this is the rule'. Her husband kept crying. The therapist came back to him and said 'is the pain still there?' Ershad cried out 'sir someone is cutting my legs from me'. The therapist moved around to the patients and replied, 'do you hear the sound of metal workshop, the welding sound? I ordered a pair of leg for you, don't worry.'

3.2 Everyday Recreation in CRP: Entertainment and fun

There is a one hour cultural program in every Saturday at half way hostel. Normally patients get admission on Saturday in every week. This cultural program is a reception program as well for those new comers. We went together on this program. Patients were ready in the hall room. In the time of getting in the hall

room, Moshiur Rahman was acclaiming at a time 'Beby Naznin has come, Beby Naznin Has come; many songs will be sung today'. Beby Naznin is a famous female singer of Bangladesh. The therapist whispered to me, 'do you know how to sing a song'? 'No' my answer. He said to the group, 'Keep silence. Let me start the program. Why we are here now? We are here to joy. We have to show something to others today. Anything; song, poem, jokes, dance anything….but we have to show'. 'But how could I dance with wheel chair?' Saiful asked laughing. Aminul vai replied, 'no it is possible, look at to me'. He started dance in his chair. Omar Farukh, a thirteen years young wheel chair person said boldly 'it's not too easy as you have shown'. Moshiur Vai was making fun with me, 'please sing a song madam, I did not listen Beby Naznin's song since a long time'. I defended myself but no luck. Aminul Vai saved me by starting a joke. In another cultural program Moshiur vai mimicked different dialect of different patients, who come from various region of Bangladesh. Not only in the cultural program, but also in the time of group therapy, gardening, leisure time, out sports they imitated different patients and their relatives. In the group therapy, one patient takes the

Moshiur Rahman (30): He was a truck driver. One rainy night, silt spread over the Aricha road (a place 50km far away to Dhaka) and his truck slipped from the high road to the valley which is about 30 miters low from the road. He got hurt in back. His lower part of the body is senseless now. He wants to go back to his old profession. Though, according to the therapists, he never can walk again. However, his wife thinks if God wants, he would be able to walk again. In different session of our conversation, he always feels proud about his recent past; about his masculinity (he could manage two or three female at a night). He also talked about his grandfather, who had lots of money, horses and two elephants.

leadership. He/she has to come in the front of all the patients and he leads the group. He does one therapy and the group follows him. If he pronounces anything in his dialect, then the whole group starts to mimic him. Very often the group leader makes fun with others' dialect. Along the leader all group members make fun at a time. In addition, they find out some words to indicate different therapy, and different events. One day, Dipu told me, 'Madam we got a polythene- khoch khoch. Come on polythene, she is our madam'. I saw the new young boy. He is not more than eighteen years old. I asked 'why do you address him as polythene?' Dipu did not tell me anything. He left the place along with the new comer. Another patient Saiful told me the story behind it. That young man named Nurul Amin just came on that day. He got his bed and arranged everything. He is the roommate of Dipu. Within one hour, he peed on his lungi and wheel chair. Then his mother put polythene on the wheel chair. As a result, when he moves they got the sound, which is like 'Khoch Khoch'. I heard Nurul Amin's name as polythene first couple of days then I found the name khoch khoch. Sometime in the group therapy, they

Dipu (18): After finishing the study of grade eight Dipu started to do tailoring. He was a paraplegic patient. His mother was very careful about him. She does each and every work on behalf of Dipu. One day, the occupational therapist brought him to the tube well, which was specially made for the wheel chair user. The therapist asked him to pump the tube well and take a bath. He seemed unhappy; his mother seemed more. He started to pump and said, 'I never pump in my home even when I was fine. Now I have to be here and have to pump.' I asked 'why?' He replied, 'I am the only one son of my parents madam, I don't need to do it'.

Saiful Azam: Saiful Azam is a 22 years old young boy. He was a wood cutter and one day from the tree he fallen down on the ground. He was not advised to bring any care giver, as he is paraplegic. At the same time many of the paraplegics brought their care giver or the relatives like to come, but I never saw, Saiful's relatives to come. He was attending the electronics course from the vocational institute of CRP. By using two hands, he could move his wheel chair, take bath, could manage the toilet and can do every day's work.

make fun with this name. In every single group therapy, the patients have to maintain a rhythm, like 'one, two, three, move more and normal'. With this rhythm they move one part of the body. However, after getting the word khoch khoch, they started to use it instead of number behind therapist's back. The patients often made different story on different patient's life. Chunnu Mia got hurt by falling from the jackfruit tree. After his admission in half way hostel, once Saiful told me that, 'madam, if you want to eat fruit, you should request. Is not it?' I replied 'yes, for sure.' 'But Chunnu vai did not request to anyone. He has gone to steal the jackfruit and fell from the tree.' Chunnu vai did not protest against Saiful; rather he was laughing considering this as fun. Chunnu vai told me in a light mood, 'madam, I think stealing fruit is 100 times better than stealing wood'. Just after two days of that day, I found Saiful in a sad mood. He discharged from the half way hostel on that day. He was waiting for his parents. They supposed to be there by noon, but they were not appeared till afternoon. At the same time Saiful could not reach them over phone. He looked frustrated. I went to him, but did not ask anything. He was very defensive; started to explain to me, 'they are coming madam. I think something is wrong. Maybe, my mother is sick. Otherwise, they supposed to be here. They are very responsible madam. Please tell sir to consider me two more days.' I said, 'did they phone you regularly?' 'Yes they did' he said. But his eyes became red gradually. I did not ask him more questions.

Chunnu Mia (36): Chunnu Mia was a worker in the export processing zone in Chittagong. On an Eid vacation he came to his home in Barishal (a divisional town in Bangladesh). By falling down from a tree in his home on that time he got paralysis. He could not go back his work place to beg the salary of rest of month or the other money like pension. His wife also worked with him in the same place. For this accident, she also lost her job. She was the only care giver of Chunnu Mia. They got two daughters. Nobody was in their family who could earn. He was planning to run a grocery shop and took a course from the vocational training centre of CRP. After one month of his discharged, I met him on a road and asked about him. He told that they live close to the CRP, as there are many industries and his wife got a job in one of those industries. He could not start his business yet.

3.3 Gender and Disability:

One day in discussion, the therapists were talking about the home environment. They talked on the kitchen environment. One therapist said, 'this is very important part for the women'. Then Hemayet Fakir (45 years old patient) protested, 'no sir, this is also important for man like us. We should learn cooking immediately. I don't know when my wife will leave me. I should take preparation from this stage.' All the patients were laughing. He added more 'look at Manjil. His wife left him. He should learn cooking.' Manjil vai was only one example in the half way hostel whose wife left him after the accident. On the other hand, out of eight female married patients, five husbands left their wife just after the accident. One young girl name Shahanaz (22) got spinal cord injury due to tuberculosis in spine. She was explaining her situation. She got a severe pain once. After suffering for seven days, she went to the doctor. The doctor gave her pain killer and after that day, she could not move her legs and hands. That time she was in her parent's home. Then her parents took her in the local hospital and then the local hospital referred her at CRP. Her husband lives in Arab. After getting

Manjil Hossain (28): He is a tetra-plegic patient. He could not move his leg as well as his hand. His father and brother used to come rotationally to take care of him. He got an accident due to a new bridge close to his home in Munshiganj (a district of Bangladesh). The bridge was too much high from the road. One day, along with his wife Manjil Hossain were passing the bridge by Rikshaw. The Rikshaw puller could not control himself when they were getting down from the bridge. It was a high slope and they all fall down. Only Manjil got hurt seriously in his neck. Before accident, they were in a joint family, but after the accident his wife left him and as well as his family. In the beginning of my field work, he said to me one day, 'apa, you are very nice, but some women's flesh should be chopped off and sell to the market'. I was surprised, because normally he does not talk much and suddenly he started talk with this aggressive sentence. I asked 'why'? He replied the same sentence again but did not give any answer of my question and left the area. After many days of my field work, I asked about his wife. He replied 'she phoned me few days ago. She was asking me what she should do. What would be my reaction if the same thing happened to my sister?'

the paralysis, her parents in law did not take any responsibilities of her. One day in a discussion, one discussant asked Shahanaz about her future plan. She did not give any answer. Her mother replied slowly that they don't want to take any decision. It is her husband's family, who could take the decision. 'But her husband's family don't take any responsibly, even they did not come for a single time to see Shahanaz' the discussant said. Her mother responded 'we assumed that they will leave Shahanaz, but we are not sure.

> *Halima (27): She lived in a house, where another family used to share her kitchen. She lived with her husband and two children: one boy and one girl. One day she and her neighbor were in quarrel because of sharing the oven. At one point, her neighbor hit her by the cook's knife. After admitting in the CRP, her husband left her. After three months of her treatment she falls in love with another patient. From the half way hostel, she went to Ganakbari (a female training centre of CRP) to trained in tailoring. I saw her once when she was taking that tailoring training and asked, 'how are you'. She said with laugh 'fine madam, but you know my husband took my son with him'. I was astonished 'what did you do then?' She replied, 'nothing. He did not take my daughter.' She was laughing that time as well. I asked again the same question. She replied that she knew it could be happen one day. She was prepared mentally.*

We will go to them. If they leave her, then we will take the decision.' Another female patient name Halima (27) was talking about her husband one day. She injured in consequence of quarrel with her neighbor. Her neighbor tried to kill her by a boti (one kind of knife), but she got hurt in her spinal cord. Her husband left her after that accident. She has one daughter and one son. During her hospital time, her husband came one day to her parent's home and took their son. She tried to protect her son but failed.

3.4 Emotional Desire

I was talking on Halima one day and one staff informed me that she fall in love with another patient name Jahangir Houladar. I saw Jahangir Houladar (27) just after one week of that conversation. After getting treatment for three month, he came to this half way hostel. He is a father of one child. I asked him several question on his life. In the conversation, he started to talk on Halima's issue. He

told me, 'madam, I try to remind myself again and again that I got one child, wife, my parents, but you know she does not want to realize. She always tells me that she will be waiting for me. I said 'no, it is not possible. What should I do now? I understood her psychological condition.' 'Do you have any care giver? Or have you shared with your family in this regard?' I asked. He said in a moment, 'no, no, no, madam. I am going back to Khulna (around 300 kilometer south to Dhaka) after two week and she will be in her home town Gazipur (fifty kilometer north to Dhaka). We will be not in touch any way.' I asked politely 'don't you love her?' 'I have some feeling for her. I can't ignore her, but I will go back to my family. Look madam, I am a wheel chair user and she is the same, how could we stay together?'

Jahangir Houladar (25): He was a construction worker at Khulna. The roof of an under constructed building fall down on his body while he was working. He lives in a joint family with seven members. The only brother and his father is also the earning person in his family. His father has a small hotel in the local market. He wants to seat with his father. I asked him 'do you know how to cook?' He replied 'yes. I used to work with my father before'. 'Why did you leave your father's hotel then?' He did not give any answer of that question.

3.5 Conclusion:

The focus of this chapter was the presentation of disability in the daily life of the half way hostel. Patients, relatives and the other staff at half way hostel represent disability through- the everyday conversation, their silent language and their reaction to a particular event. Same kind of physical disability could be different due to gender difference, economic condition, and cultural condition. The patients, who come from urban area, treat the rural patients in a different way; they often make fun with the village patients' dialect, dresses, and style of doing works.

Chapter Four: Disability in the Half Way Hostel

4.0 Introduction:

There are some rules and routine in half way hostel. Patients and their care giver are supposed to follow that routine and rules. Very often I found the routine are contradictory with the clients. These contradictions create a shape of half way hostel's culture. This chapter is a discussion of that culture, where the interaction of CRP's rule and patients & their relatives' reaction on those rules plays a vital role.

4.1 The care giver at half way hostel

When the new patient, name Shanto, could not move his leg in the group therapy; his mother came to help. She moved one leg too fast; Shanto could not adjust with the speed and came down from the wheel chair. His mother got anger and slapped to her son. Shanto, the 22years young boy became nervous; not only for the slap but also for another reason. When he was getting down, his lungi moved up. We all saw the pressure sore of his upper part of the leg. The therapist spoke loudly 'why have you slapped him? How did he get the pressure sore?' She told that she does not know and she is also suffering with her son's pressure sore. Every day, she has to take care it as well as she has to do the other duties for her son. She could not speak more as the group therapy started.

In another day, Alauddin was in group therapy. His care giver supposed to be in the group as he could not move his legs and hands. At the same time care giver are taught therapy, as if they could help the patients back home. Whatever, Alauddin's wife was late. When they moved their hand, his wife went to help him. It was tough for her and Alauddin got hurt. Suddenly he shouted harshly 'Get out of my sight. You Prostitute (shor magi)'. His wife replied in a same way, but we could not get her speech. She left and Alauddin had a look whether there is any reaction within the group. On the other part of this group therapy, Lakkhon Das was

present with his nephew. On that day he got the permission to go back home. Lakkhon Das is a man of 45 years. On the other hand his wife is only 20 years old. His nephew came just one day before his discharge. After half an hour of the group therapy, his wife came to help him. She laughed timorously to her husband and nephew. The nephew, who was the same aged of his aunt, shouted ignoring all the people of that room, 'you always misguide my uncle, don't you? You move the hands and legs in wrong way. What did you learn in these two weeks? Why did we send you here?' The aunty became more nervous. She told something in a spongy voice. I could not hear her voice but I heard her nephew's reactions 'you don't need to be here. Go to your home and take your makeup, isn't it what you give more importance?.' Matin Sharker reacted on that time; he said to the nephew, 'young man, you have the hot blood. If your aunty leaves your uncle, your uncle will not find you in your aunty's place.' Matin Sharker got his wife as care taker. Once, his wife was telling me about their conjugal life that they did not have any problem. They were a happy family. They got some paddy land in Narayanganj (an industrial district in Bangladesh) and this land is the reason of all problems. The local brokers were trying to buy that land for constructing an Industrial site. He did not sell it, so they hit Matin Sharker with a cooking knife from the back. She was crying at the time of telling that story.

I got only four patients who were alone. The relatives who were not allowed to stay in the hostel, they rent a home outside of CRP and look after their patients. Most of the care givers were mother or wife. I got 32 married male and 24 got their wife as care giver. 20 were unmarried male and got their mother as care giver. On the other hand, within 9 female married patients four husbands left their wife just after the accident. Two husbands were the care giver out of these five husbands. Three patients lived alone and others got their mothers as care giver.

One day I was talking with a female patient name Shahanaz (22). Her husband lives in Arab. After getting paralysis, her husband stopped all kind of communication with her. During the treatment period, she got her mother as care giver. I asked her about her plan to stay in future. She said now only one place she has; that is her mother's home. At least her mother cannot ignore her.

4.2 Disability in discussion and the encounters

The councilor comes to discuss with patients from social welfare unit of CRP once a week. He has a bold and dominating voice. He started to speak one day. He spoke many things on the duties of a patient; he especially talked on their behavior. He told,

'Look, you have to be well behaved with your relatives, especially with your care giver. Before, what happened? You came and say, "give me rice now (taratari vat de)". And your wife is always ready to do so…why? You were the earning person then. But now….now you are the burden. If your wife leaves you, you will not get another person to marry. So, don't raise your voice like the past. At the same time, I would request to the care giver, please don't be rude with your patient. It could be happen with you in a second. After an accident you might become a paralysis patient. If the patient does any wrong to you, give them the opportunity to feel guilt for what they have done. Open the lock with key, don't use brick to break the lock (Tala khulte chabi bebohar koren; it dia tala vangte jaien na). It will not bring a good result.'

The councilor was talking without intervals. Then he started to talk about the other medicine systems. He started again,

'One man took treatment from CRP and then back home went to a Kaviraj (traditional healer). Kaviraj gave him the heat (shake). And what happen then? That patient died with skin disease. The infection due to burning spread out to different part of the body and he died at last. Do you hear me? Do you believe me? No, you don't believe me, I know. I know that for sure. If you believe me then, you should not go to the kaviraj. But I know, in the time of home visit, I will not get you in home. Where you will be then? You will be in kaviraj's home for sure. Is there anyone who can say that, I am not going to kaviraj. Is there anyone?'

Nobody gave any answer within few moments. Then Mashiur Rahman said in a low voice 'but Sir, one man in our area became fine again after getting treatment from a kaviraj.' The therapist started to talk now, 'look, there are many problems

with bone, which is automatically healed without any treatment. Your kaviraj just passed time and the bone took its previous shape (ager shape fire asche). And you think the kabiraj made it successful.' Now another patient name Chunnu Vai said 'no Sir, it might be happened (Na Sir, eta hote pare).' We could not hear the explanation from Chunnu Vai as the discussion time was finished and the patients had to get ready for the individual therapy.

Apart of the councilor, half way hostel has different discussant; like the vocational trainer, social welfare worker, and general physician. One day the vocational trainer came to discuss the patients plan for future. One patient name Shahin (35) was a day laborer. He had to carry heavy load on his head. After his accident, he could not move his hand and leg. Once the vocational trainer asked him about his career plan. Shahin said if God wants he will be back in his previous profession. The therapist said, 'how come? You will not be able to walk again, how could you think to lift the weight again?' Shahin did not tell anything. The trainer asked again, 'what is your plan then?' He said that he will run a small shop in the rail way station in that case. The therapist said it could be a good idea. As he could not use his hand, his wife can help him in this case. Moreover, his wife could take a tailoring training at CRP. Then she would be able to run the family. Shahin resisted at this time 'what could be done by a female (meye manush abar ki korbo)?' The therapist became angered 'what did you say?' Shahin could not tell anything. The trainer started to explain again the necessity of work for the disabled.

4.3 Expression of Pain and Language to indicate the disabilities:

'The flesh of my leg is jumping (Amar paer mansho ta lafaitase)' Chunnu vai told it by showing his upper part of leg. The therapists told me, 'do you know, what it means? It means he got Convulsion. This is a good sign actually. He has some feeling in his leg. That's a good sign.' Hemayet Fakir told from another corner of the hall room, 'Sir, I cannot tolerate this good signs (Sir, beshi valo to ar shojho hoi na)'. The therapist replied 'do you know why it is good for you? Look, ants have bitten Chunnu's feet, but he could not feel it. If he had feeling then the skin could alert him about the bite. Now it could turn as a major problem. Do you see what I

mean?' Hemayet Fakir did not tell anything. After the office time when all therapists and staff left, the patients and their relatives often chat about their pain, their physical condition, future plan and so on. They use different words and sentences to indicate there pain. Most of the time they have used shock (chilic mara), shake (khichuni), and burn (pora). The patients as well as their relatives also used many different terms to indicate disability. 'Lengra (Who does not have leg)' was the common word in Bangladesh. However, when I asked to the patients and their relatives about the local word of disability, they became really tense. Most of them said, 'Pongu'. Pongu is a modern and correct word according to Bengali grammar for that person who has a problem with his legs. Some of them said the word 'lengra', which word is usually treated as slang for 'pongu'. However to indicate the opposite situation of disability, they always use the word 'valo manush'. Literally valo manush means good man, but here they mean good health or sound body. At the same time, very often they said, 'I hope, I will be good again to work'.

4.4 Outing and Cultural Program: the formal entertainment of CRP

Usually the Thursday is the discharging day of the patients. The discharged patients, who are able to visit, go for outing in every Wednesday. After some days I found the patients only go to the National Monument. The National Monument of Bangladesh is only six kilometer away from CRP. I asked the care taker of the half way hostel, 'why you are visiting the same place always?' I did not consider the patients around me. He gesticulated and said, 'they see the monument in the TV news every day. They like to be there. When they will go back to their home, their relatives and neighbor will ask them about this monument. It is shame for them if they can't tell them anything about it; after all they have been living here since couple of months.' He told me after few minutes that CRP does not have much money to take them different places, where there is an entry fee. He alerted me as well not to disclose it in front of the patients.

CRP's vehicle cannot transport too many people for outing. Only five patients along with their care giver and wheel chairs could go from the half way hostel. The

patients, who don't go for outing, stay at the half way hostel for the cultural program. I asked Rejaul Karim (38), 'you have not gone, but you will leave soon.' He was laughing at me. He said few seconds later, 'I know all place of Bangladesh madam. I went everywhere with my truck. I visited national monument several time, I was not always like now madam.' I knew he was a truck driver, but it did not come to my mind on that time. I felt shy for that.

4.5 Occupational therapy and the occupation of the patients:

There is a Rikshaw[3] in the half way hostel. Occupational therapists use it to provide therapy to the patients. Patients learn how to ride on a Rikshaw from the wheel chair, how to put the wheel chair behind the Rikshaw and so on. One day a female patient, name Fatema(35) was requested to get on the Rikshaw, but she refused several time. She seemed shy in front of all people. Later I asked her, why she did not try to get on the Rikshaw. She explained me that she did not ride on a Rikshaw too many times and after the accident she assumes that she has to spend rest of the life in home. For her it is not useful anyway. I got also some young men, who usually did not pump the water from tube well. Their wife or mother usually arranged water for them and after bath these women clean those clothes. However, as an occupational therapy, they have to pump the tube well and clean their clothes every day. Fatema was shy to say that Rikshaw ridding is not useful for her, but these men said proudly that cleaning and pumping are not male-works.

In addition, once or twice a month, patients are bound to clean the whole hostel. They have the long sweep and cloth to clean. Normally, patient's care giver come to help them. One day, Rezaul Karim said, 'madam, I never did this kind of work in home. This job is for female. Now I am disabled and it is more like I am a female and I have to obey their command.'

4.6 Conclusion:

This chapter is a discussion on different events and aspect of half way hostel. One of the most important focuses of this chapter is the care giver of the patients; the care givers' type, patience, future plan, expression of their feelings are the major

discussed area. Another important part is the discussion of the half way hostel and patient's own agency. The perception of the discussant and the perception of the patients are not the same always. They have their own agencies; own way of protecting their opinions. Patients' language is also an important part for this chapter. In this paragraph, I really faced problem to explain, because patients along with their relatives used many local words those are too tough to have a proper translation. Moreover, the facial expression, the body language and my interpretation are might not be able to show the true situation. However, with this limitation I described the expression of pain and those words they use to indicate disability in their daily life. I also discussed here the different idea of CRP, like outing, occupational therapy, cultural program and the conflict with the patients' practical life.

Chapter Five: Conclusion

5.0 Discussion

All the patients of half way hostel come to CRP or other medical centre directly after their accident. As a result, they do not know what is going to happen in their home environment with their new physical condition, rather they know the name of their physical problem according to biomedicine, the causes of this problem, present situation of the body and so on. They are very eager to take bio-medicine, though these medicines are very often not related with paralysis; rather related with the headache, seasonal fever, stomachache and some time for pain. Nurses bring prescribed medicine to the specific person everyday at 1.00 pm to half way hostel. I saw many patients, who are not prescribed to take any medicine, but they came and asked for medicine. They also know the governmental remuneration for the disabled. There are many causes behind of this kind of biomedicilized thinking of the patients. One of the most important causes is the daily discussion in half way hostel. Six days in a week, CRP arranges a one hour discussion for the member of half way hostel. This discussion is run by the therapists, social welfare worker, counselor, and the vocational trainer of CRP. This discussion is about physical hygiene, health situation, vocational training, better home environment, social security, and patients' psychological condition. Through these discussions, all patients got the idea of their physical and mental health, their better future home environment, future professional plan and social relationship, those are highly biomedicalised.

At the same time, half way hostel shows a film in every week. CRP by itself has produced four film name Bihongo (The Birds), Radio- vai (The Radio Brother), Porisker- Poricchonnota (Clear and Hygienic), and Wheelchair. Each and every film has some optimistic massages for the patients. In every film they show one disabled is a hero and very conscious on his physical condition. His surrounding people always try to neglect and insult him, but he always try to ignore it. Very often he teaches the

others how to treat a disabled person, how to behave with them. However one part of the society always stands against him and another part is always with him. At the end of every film the hero succeed to get the heart of the most of the people of the society.

Through these films and discussion, CRP also makes their position against the local healer like Pir and Fakir. However, though CRP tries to influence the patients from their biomedicalised point of view, patients have their own type of medical pluralism as well. Among my informants, some patients show their soft corner for the effectiveness of the other medicine systems. This is also because of the gaps between the staff and the patients. These gaps are mainly based on their different languages. All the therapists and most of the staff completed their study in English version. As a result, in discussion they use many English words, especially when they pronounce the name of different part of the body as well as the name of diseases. Very often patients don't understand that. The opposite scenario is also common over there. Some English word like 'CRP' is a well-known word in half way hostel. However the elaborated form of CRP (Centre for the Rehabilitation of the Paralysed) and the Bengali of that elaborated form (Pokkhaghat der jonno punorbashon kendro) are not familiar at all for the patients and for the local people. That is why, when the discussant use the Bengali form of CRP, the patients looked so confused. Dialect and different style of pronunciation is another factor for this gap.

Apart of this language problem, economic and cultural differences are also grounds of this gap. Very often, the stuff deal the patient's physical condition in one way and the patient himself deal the condition in another way. I got one patient named Monir, who wanted to go home and the therapists did not give permission. The therapists thought that, he is improving and he should stay one week more, though, Monir has passed his estimated time in Half Way Hostel. His father just came to take Monir. His father said to me, 'look sister, this is harvesting time. I got at least two hundred taka (taka is the Bangladeshi currency) in a day back home. But sir (the therapists) told me to stay one

more week. By this time, I will lose one and half thousand taka. On the other hand, the bus fare is also high. It's not possible to go back and come here again after seven days. Please sister, tell him to release us. My wife is also very sick and alone over there.' I conveyed this massage to the therapist and they said to me, 'try to understand, he got the pressure sore and could not seat in a wheel chair as a result could not attend in any therapy. However, he is improving and there is huge possibility of maximizing the development of his physical condition now. With this one week therapy, he will improve a lot.'

In the half way hostel, patients have their own future plan. At the same time the relatives of the patients have also some plan for the patient's future. One patient named Belal, his mother is a talkative woman. She was saying in an afternoon one day that Belal is going to marry his paternal cousin, who is not fair enough. Belal is a spinal cord injured patient, who could not move his leg. It was even a tough job for him to move his hands, as he got hurt in his neck. All the members were laughing with Belal's mother's comment, but she was serious. One of the audiences asked her, 'do you think your brother in law (bride's father) will offer his daughter to your disabled son?' 'For sure' she replied, 'but she is black and my son is also black. I am thinking about the next generation'

Another two patients, name Azhar who worked as a soldier in the border of Bangladesh and Rezaul Karim who was a truck driver, think they will go back to their old profession. Both of them can walk with the help of walking frame. However the therapists thought, this is absurd, because they will not get enough strength to walk effortlessly again. Not only these two patients, all the patients think that, if God wants they will be cured again. Though according to CRP, spinal cord injury is not completely curable anyway. After getting a long term therapy, patients can improve a bit. However, it also depends on the scale of the patient's injury. Another patient named Manik, was really optimistic in the primary stage of his accident. He was active

and wanted to do all the therapy with much curiosity. Afterward, I found him inactive and often tired in different activities period. Once I asked why he is not responding like before. He replied, now he knows he can never be ok again. He is fed up with this every day's exercise; even he does not know when he will become a bit better than the present.

Apart of these frustrations, I saw many fun and comedy at half way hostel every day. They have their own kind of hierarchy. They got the hierarchy between tetra-plegic and paraplegic patients, between different economic classes, between different regions and so on. They often make fun for these hierarchies. For example, someone from Dhaka or close to Dhaka often make fun with the dialect of a person from a remote area.

5.1 Conclusion:

This chapter shows the findings of the study. These findings are ordered in a descriptive style by avoiding the concrete points. One of the most important findings of the study is that the patients of half way hostel are highly biomedicalised, because of the different activities of CRP e.g. daily discussion, film show, and counseling. The next finding of the study is the agency of the patients, where the opposite scenario of the first finding is prominent. Though patients are motivated to be more biomedicalised, still there are many patients who would like to try with other medicine. The communication gap (for different language, different culture, and different economic and educational background) plays an important role here. Patients' daily life; his fun, frustration, representation of disability, relation with care giver, dominance of male patients and female patient's male relatives are also some important feature of this study. By these features, I narrate the culture of half way hostel. I showed here that disability could not be explained by any model; like social model, individual model, or biomedical model. Rather it is much more related with the local cultural context. According to those models, disability is always a matter of bad

luck and disabled person suffer a lot. In my study, I did not see a black and white picture of disability. They face different difficulties in the daily life, however, at the same time they are not complaining always for those difficulties; rather they make fun by imitating another friend of them, dreaming to have an able body again, making their imaginary world and so on. They are frustrated in some extend, but this is not the final word. I saw them to compare their life with other severe patients as well as his previous worse situation; they discuss on other medicine systems, which might be more effective to cure their present disability.

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