UNIVERSITY OF GOTHENBURG
**DEPARTMENT OF SOCIAL WORK**

# Challenges of Retinitis Pigmentosa (RP) Patients in Iran and Sweden (A Comparative Study)

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# Abstract

This research is based on a comparative qualitative study to raise the challenges of Retinitis Pigmenthosa (RP) patients regarding the three levels of their life as well as the relationship of these levels through living with RP, in two different contexts of Sweden and Iran, in order to contribute in improvement of RP patients' life conditions and reducing their difficulties. Fifteen semi structured interviews were conducted to RP patients from Iran and Sweden. Five respondents lived in Iran and ten, in Sweden. Three respondents were services providers; an Ophthalmologist, a social worker and an eye pedagogue.

The research questions include the patients' challenges in three levels of life, the influence and interconnection of three levels of their life, their coping with their disease and their participation in improving the life conditions of disabled people.

According to research findings, RP patients in both countries deal with stigmatization and exclusion in three levels of their life. Lack of public awareness and stigmatized normative public approach lead to exclusion of RP patients from social support, family and friend relationships. It also excludes them to get social services and public facilities (e.g. public transport) in macro level. Community is a good resource for RP patients to increase their individual and social acceptance. These activities provide opportunities to expand their social network, exchange their experiences about coping with RP, share their common experiences and decrease social segregation. RP patients' participation in formal and informal communities is an example of utilizing their collective power to influence the efficient factors in macro level, factors such as policy makers and authorities, in order to enforce their rights and fulfill their needs.

**Key words: Retinitis Pigmentosa, Challenges, Stigmatization, Social Support, Community, Coping**

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# Acknowledgement

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Finally, I dedicate this study to all Retinitis Pigmentosa patients all over the world.

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# Chapter one:

## 1.1.Introduction

Retinitis Pigmentosa is a type of visual impairment which bothers 3.5 million people worldwide. RP[1] patients are dealing with unique individual and social challenges and barriers in their daily lives which distinguish them from other visually impaired and disabled people. RP people are voiceless and a minority group in social studies and debates. I believe that RP patients are experiencing specific individual and social challenges which need more focus and study. These daily challenges might be originated from social and structural shortages and oppressions which disadvantaged this group as the voiceless and excluded member of disabled groups. RP patients deal with unique individual and social life which needs more awareness, and education. These shortages in different levels of their lives might come from attitudinal and structural barriers. Specific characteristics of RP develop physical limitations and difficulties that need to be raised in public education in order to reduce their social oppression mostly originated from low public awareness and stereotyping norms applied to the people with visual impairment. (http://www.rpinternational.org/about-rpi/helen-harris.html )

**What is Retinitis Pigmentosa**?
“Retinitis Pigmentosa is an eye disease that damages the retina. The retina is the layer of tissue at the back of the inner eye that converts light images to nerve signals and sends them to the brain. Retinitis Pigmentosa can run in families. The disorder can be caused by a number of genetic defects”
.(http://northside.adam.com/content.aspx?productId=101&pid=1&gid=001029)

“The cells controlling night vision (rods) are most likely to be affected. However, in some cases, retinal cone cells are damaged the most. The main sign of the disease is the presence of dark deposits in the retina. The main risk factor is a family history of retinitis Pigmentosa. Retinitis Pigmentosa is a group of inherited disorders in which abnormalities of the photoreceptors (the rods and cones) of the retina lead to progressive visual loss. Essentially, Retinitis Pigmentosa patients deal with defective darkness adaptation, then constriction of visual field (tunnel vision).” The symptoms of RP may emerge at any age but most commonly they become visible in young adults. Generally, the disease has more severe symptoms when it begins in younger ages. Occasionally the disease is present at birth and can be diagnosed with appropriate testing at that time. RP

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[1] Abbreviation for Retinitis Pigmentosa

is identified as one of the most common inherited causes of blindness in people between the ages of 20 and 60”.
( http://www.medterms.com/script/main/art.asp?articlekey=22264 )

I noticed that Retinitis Pigmentosa patients are voiceless minorities among other visually impaired and disabled people. In fact, there are few studies conducted about this group and with medical approach only. It is necessary to focus on RPs social life conditions as well as their challenges. Increasing the public awareness about this group of people, their characters and their rights, may be quite useful to improve the life conditions of this group of visually impaired people.

**RP patients in Sweden and Iran:**
According to statistics, 3000 people with Retinitis Pigmentosa live in Sweden and 4000 people are registered in RP Association in Iran, but based on interviews with active RP patients in the Iranian Association for Protection of RPs, they claimed that although just 4000 RP patients are registered in RP Association, but they estimated that 70000 people have RP in Iran. Unfortunately lack of integration, and not satisfactory access to RP community, also the poor social network, are the main causes of unreliable statistics regarding RP patients in Iran. Consequently, many RP patients do not have any access to social services in different parts of Iran, for various reasons. (http://www.djurforsok.info/nyheterreportage/nyheter/lovanderesultatfornathinneforskning.4.20a9b749116aab4d13680001501.html )

In this part I will explain the information I was given by an ophthalmologist who was specialized on RP for 35 years in Gothenburg. RP is a genetic disease which disturbs metabolism in retina. The retina’s receptors do not rebuild the taken light fast enough. Hence, some parts of retina function more and more difficult. The RP patients do not realize their disease in their childhood because of enough light. If they live in the country side, they usually recognize RP easier, because it is darker and they are very sensitive to light. In typical RP the vision field is gradually lost. They lose their function to orient as well. RP is a recessive inheritance disease. When the people with RP lose their functions in their vision, they look very curious most of the time, because they cannot find people around. The important signal is that they look very well in to your eyes. If they have a central visual defect they see a little better than that by retina. They can work with computer, they can write and read very small signs but they cannot find their friends when they are out e.g. in a café. Indeed many of them have a problem in following friends in outdoor activities and gatherings. So they always find apologizes not to join the gatherings, because they do not like a light at the table, they do not like the darkness, they would not tell that their vision is low, they do not dare to ask the boss and colleagues to help them to find the toilet. It is very common for them to hide their RP and it seems that it is because their eyes function so well till the last moment when their visual field breaks through. It usually happens very late when they are graduated, qualified and have a job. At these circumstances they naturally wish to be like other people. It seems that it is a serious social problem. There are lots of misunderstanding among ordinary people about this problem. Understanding of visual loss of this group is very difficult. It is difficult for ordinary people to understand the patients when they ask for help e.g. in taking a bus. Because the people think that when one can read books and newspapers without any help, how they ask for help for some other functions like catching buses. So it is very strange and hard for ordinary people to get the point about these groups.

### 1.2.Social Complication

Undoubtedly that People with RP deal with lots of difficulties in different levels of their life, such as individual and social life. They suffer from discriminations in various aspects of their daily life. For instance, they are excluded in their family relationships and friendships. Moreover they face some mistreatments in public places. They do not have full independency because they do not have easy access to public transport and public places, therefore in many aspects they need to ask for help. So living with RP limits them in many aspects of their daily life. They experience discrimination through exclusions and rejections in family relationships, friendships, labor market and generally speaking, in social community and finally they socialize this rejection in their individual life. Some parts of this discrimination originate from defined norms and ideals in society which shape all individual and public attitudes in the family and friends' environment as well as public places, educational system and media.

Here, the information I received from the ophthalmologist about the social challenges of RP patients in Sweden, are represented:

Based on Swedish Disability Legislation all the disabled people including blind and visually impaired are financially supported by the government and social system. But regarding RP patients the service providers are not familiar with this disease, therefore they are not justified that RPs are actually liable to get the financial support and refuse to do that. The eye doctors usually have to send documents to prove the blindness of their RP patients, so they can use this financial aid.

Because of the poor vision, the RPs are not able to drive. In Sweden the disabled people can get benefit of special taxis, but this in not either applicable to RPs. Because RPs are no recognized as disables. In Sweden it is difficult to get a job when one has a functional disease, so it seems that part of these problems regarding employment are due the fact the RP patients do not announce that they have this eye disease. RPs hide their disease because the development of the disease is very slow and they have to adapt with it, and they do not face real problems until they lose their central vision. Some doctors have to tell the RP patients that they are going to lose their sight completely, so they believe that they are disabled. It is part of their rehabilitation policy and a rough way to help them. The problem with this disease is that brain does not understand the deficiency; therefore the person involved does not believe that they cannot see properly. Eye clinics have special groups for patients who lose their central vision, otherwise they would get depression. RP has different types, so physicians can never tell the patient what is going to happen. They can tell them that you probably will get low vision. It takes a long time for the RP patients to believe that they are disabled; it takes a long time for them to accept using white cane because white cane is a very hard sign of blindness. The first and the last vision loss are the most difficult parts of the disease. When the patients lose the last vision acuity then they will be dependent on other people.

### 1.3.Social policies for people with disabilities in Sweden and Iran:

Both Sweden and Iran have ratified the declaration of rights of people with disability. (http://www.un.org/disabilities/countries.asp?navid=17&pid=166)

The national policies for protection of disabled people have been reviewed briefly in both countries, in this research work. It seems that enforcing these policies strongly, depends of power relations and structural system in both societies. This will be theoretically discussed in analysis chapter.

Swedish disability policy was implemented in 1994.Considering this policy, people with disability have rights such as equality in education, funding to find jobs, modification of their housing , ease of access , transportation and car allowance. Special assistance is provided for children with disability regarding to education right. According to the right of finding jobs, state is establishing labor market agencies which find jobs for people with disabilities. People with disabilities receive various types of financial assistance from the Swedish Social Insurance Agency in order to th support them to cover extra costs arising from their disabilities. Considering the right of the ease of access, public places can be used by everyone. As regarded to modifications for housing, disabled people have access to municipal grant to modify his or her residence. Grants contain all types of functional disabilities, such as mobility disability, impaired vision, mental disorders and allergies.

Group housing is accessible for people who need extra support. Another alternative is service flats, a completely independent type of housing where people live in their own apartments but can call for staff at any time. Family homes are accessible for children with functional disabilities. These permit the child to live for certain periods with another family. (http://www.sweden.se/eng/Home/Society/Accessibility/Facts/Swedish-disability-policy/)

Enforcement of Freedom of Speech among Disabled People in Sweden:
There is an opportunity for Swedish disabled people to modify and improve their social rights and policies. They have freedom to transfer their comments and challenges to policy makers who are participating in congress. Every Thursday they demonstrate outside Swedish parliament (Rosenbad) in Stockholm. Usually, they distribute some brochures to politicians which contain their challenges and their recommendations in order to improve their social situation.
(http://www.srf.nu/pressrum/nyheter/torsdagsaktionen/)

**Iranian Comprehensive Legislation for Protection of Disabled People**:
In the following section I have briefly reviewed the legislation of social policies for people with disabilities in Iran.
According to this legislation, people with disability have access to half price transport ticket and half price benefit for using sport facilities. Moreover, disabled people who are registered in social welfare state could have health insurance for disabled people and supplementary health insurance. Furthermore, disabled people are exempted from military service. The government is bound to allocate at least 3 % of employment permit to ministries, organizations, companies and public institutions, to hire qualified disabled people. Disabled people who are registered in social welfare state do have a right of free education in all governmental universities, agencies and institutions. Ministry of housing is responsible to give 10 % of residential units to disabled registered people in social welfare state, Access to standardized public places, rehabilitation activities, and allocation of 2 hours of weekly media programs prepared to increase the public awareness about rehabilitation of disabled people, are some other legislation on the benefit of the disabled. Despite of ratification of legislation for people with disability, Iranian government has not been quite successful in enforcing some legislation in different aspects, such as accessible public transport, standardized housing, secure and standardized streets and public places.
(http://iransdp.com/?part=menu&inc=menu&id=1473)

## 1.4.Aims and Objectives of Research:

The main purpose of this research is to investigate factors which can be efficient in life satisfaction (situation) of RP patients and to find out their challenges in personal and social life, according to individual, social, structural and environmental barriers. Furthermore, it might be necessary to explore the relationships between these levels of life in order to explain their social Oppression and exclusion. Three levels of life have been taken from Socialist-collectivist perspective of Payne .(Payne,2005,p.9)All these efficient factors between Sweden and Iran are compared in this study to show a clear picture of RP patients' life challenges in different aspects, and in both countries. Finally, it is hoped that this study would be a step towards more research works and consequently to improve the life conditions of RP patients in both countries.

## 1.5. Research Questions:

1. What are their challenges in the Micro, Mezzo and Macro levels of their life?

2. How these three levels of RP patient’s life are interconnected and influence each other?

3. How do RP patients cope with their disease and social limitations personally?

4. How do they participate in improving the life conditions of disable people?

# Chapter 2:

## 2.1. Literature Review

There is no study focused on individual and social aspects of RP people's lives, but there are many studies with medical approach about this topic. Indeed I have found other studies about visually impaired people which are focused on different aspects of their life challenges such as access to information, social exclusion and access to social service.

Some of the literatures are briefly reviewed:

Gullacksen (2011) has focused on life adjustment process related to acquired deafblindness.This is based on qualitative focused group. It is a comparative study between Denmark, Norway and Sweden and is published by Nordic Centre for Welfare and Social Issues. This study is focused on individual experiences of building up the life situation based on the conditions created by deaf blindness. Results illustrated that satisfactory life is vulnerable to external changes that are out of one's own control. The informants have described the future and life with deaf blindness using a modulated confidence and a balance between restrictions and possibilities. They outlined that the life adjustment is a long and tiresome road to travel but they learnt to live with it.The common point between this research and my study is investigating the life adjustment. I have studied individual acceptance of RP patients as an important part of their life course. Another similarity of this study is studying about the deaf blindness people who have common characteristics with RP patients in losing vision. (Gullacksen, 2011)

A workshop in Oslo University (2004) has focused on the provision of low vision services which may prevent continuing levels of disability. There are services that might allow better quality of life, education and employment. If more people know about the availability of such services, this would increase the level of acceptance of using these devices in public, and more people would get appropriate care. This workshop has the aim of encouraging all international efforts towards blind prevention to identify the needs of visually impaired people. (Oslo University, 2004). Focusing on accessibility of social services for visually impaired people and public awareness is a common point between this workshop and my study.

The qualitative Study of Bultjen, stead and Dallas (2002) represented the particular position in mainstream schools and give a clear message that inclusion can and does work but all authorities and schools should be further encouraged to fully embrace inclusive policies and practices. This study is related to interpersonal relations of visual impaired people within local communities. Here, I have outlined the results of this study. This project concentrated on children and young people in mainstream schools. Pupils, parents and teachers all talked about the importance of teaching staff being knowledgeable about visual impairment; the importance of support being available, the importance of communications (between teachers, between pupils and teachers, and between teachers and parents); the importance of friendships and positive social interactions in school; and, the importance of involving pupils in decision making that affect them. The pupils in particular, highlighted what helps to make them feel included in school, and equally treated what it feels like when they are not. However, schools are part of the local community; pupils need to feel that they are also part of the community. Moreover, social inclusion is an important part of government policy. Social inclusion can have many interpretations depending on the context. Furthermore, social inclusion is not a one way process that is the responsibility of only the visually impaired pupil, as many are socially excluded because their visually unimpaired peers do not know how to include them. The attitudes, empathy, knowledge and understanding of peers and teachers are the vital ingredients of feeling happy, safe, and included in school. This study is related to my research through raising social inclusion of low vision students and it outlined the role of community and government in inclusion action.(Bultjen , stead & Dallas, 2002 )

Awan, Mahar and Memon, 2011 have also carried out a quantative study which considered the influence of social barriers on their individual life in Karachi (Pakistan). Social exclusion and rejection of the blind are the consequences of negative perception about blindness. The blind cannot participate in the decision making process and have limited opportunities for education and employment. Indeed they are dealing with low self-esteem. Moreover, depression is a result of limited social contacts accompanied by loss of employment. (Awan, Mahar and Memon, 2011).This research has focused on social exclusion and attitudinal discrimination of visually impaired people about which I have focused the issue about RP people.

John Percival (2003) indicated that "Visual impaired people may not want to burden their family with all their problems. Some interviewees mentioned that they prefer to talk to someone outside their immediate family because there are some things that you do not want to tell to your family". Respondents were less reliant on family members if they had someone else to talk to, about their worries. Inability to express feelings and problems can affect mental health. This study also pointed out that peer support groups provide an opportunity for people to socialize and have some human contact". Percival has emphasized on ways in which social care provision influences the social inclusion of blind or partially sighted older people in United Kingdom. He has proposed that poor self-image and problematic emotional reactions to sight loss influence older people's motivation to go out, increasing the social isolation. Lack of someone to support individuals ended inreducing an individual's potential social interactions. Social workers, rehabilitation officers and voluntary sector organizations should provide awareness training to staff in hospital eye clinics. This research is contributing my study in third level which notices challenges of RP patients in relation to social services. RP patients are dealing with unawareness of service providers about RP symptoms ( Percival, 2003).

Chifamba, Mvundura and Tagarirofa (2001) have conducted a qualitative research methodology in which unstructured interviews and focus group discussions were the main data collection instruments. This study which is related to macro level challenges of RP people in my study, in the matter of social media and its effects on structure of society was conducted at Pennsylvania University. They outlined the "Gidden's postulations on the duality of structure also have been mentioned that the structure made social action possible, while social action makes those structures."The mass media as a social structure, whose very nature derives from the agency exercised by those who own and control it". This qualitative study found the conceptions and experiences of those with blindness were disadvantaged by attitudinal stigmatization, crude misconceptions and the politics of exclusion by the media. The research investigates and captures the conceptions and experiences of visually-impaired audience on the mass media's social marketing of HIV and AIDS information, to examine and establish official insights into how the mass media raise the dissemination of HIV and AIDS education to those with visual impairment and to establish how the visually-impaired cope and manage with the limitations in the mass media's approach in socially marketing the HIV and AIDS. These largely critical perceptions and experiences included discriminatory HIV and AIDS educational material, regarding the 'blind' as asexual, exclusion from key media positions and prioritization of the economically productive (Chifamba, Mvundura & Tagarirofa, 2001). I have implied this study related to my research in macro level view. How mass media can exclude visually impaired people and how mass media and structures can define and socialize public awareness about minorities in society and internalize stigmatized normative approach against visually impaired people in Macro level while excluding the visually impaired.

Palmer also pointed out that, low vision services performing to high standards can have a positive impact on the quality of life of visually impaired people through his qualitative study in Glasgow. The service needs to operate within a climate of high public and professional awareness of the benefits that low vision aids can bring. Optical and non-optical elements of the service need to be integrated and the service needs to be easily accessible. Encouragement, information, training and support should be part of any model of service delivery so that an individual can make a decision about how and when they use low vision aids. The study also has outlined the complicated relationship between people and assistive devices. (Palmer, 2005)

Inglis, (2006) has undertaken this qualitative survey firstly to see if in New Zealand, blind and vision-impaired people were less favored in comparison with other disability groups as potential employees; and secondly, to determine employer attitudes and perceptions towards employing blind people, and how or why these attitudes and perceptions influence employers to neglect the blind and vision-impaired when employing staff. 102 employers have taken part in a telephone survey and, of those, 6 were interviewed again in an in-depth face-to-face interview. A combination of attitudinal and perception survey instruments were utilized. The research found that participants had mainly conducive attitudes towards blind and vision-impaired people. However, in total contrast, blind and vision-impaired people were considered the least suitable or least employable positions (Inglis, 2006). This study has confirmed my findings about normative approach of employers about RP patients in both countries. According to this approach, RP patients as visually impaired are not in priority for employers in order to be able to enter the labor market.

Kamali, 2011 has done a review study about the situation of disabled people in Iran. Despite the persistent development in the cognition and providing services in Iran, the disabled are still frequently unable to make a strong social presence, limited by the inadequate facilities, and lack of enough understanding from their families who prefer that they stay indoors. Inaccessibility of buildings and other environments along with the lack of accessibility in sidewalks, public areas, educational, medical, and official buildings, shopping centers, recreational and sports centers and other public places have created a situation that is far from acceptable and will remain so for years to come. Families and disabled individuals have many difficulties with housing, employment, public transportation and also limitations, deficiencies, and high prices of rehabilitation equipment and facilities. As a result of low income and financial problems of many disadvantaged families, the solution recommended by NGOs up to now has mostly been to supply pensions, the low amount of which, unfortunately, is not a dependable source of comfort; especially in families with a disabled individual where the factors belonging to the specific kind of disability are not taken into account. Negative assumptions about disability is a main reason for the inadequacy of financial support, with many argues about how the needs of the disabled can be considered when the needs of even the able have not yet been fulfilled. In order to expand the culture and knowledge of disabled people in society, there is a solution to enable disabled children to study in normal public schools with other children. (Kamali,2011)

Moeini (2011) has outlined the general achievements of NGOs and obstacles that change their activities. This essay investigated the stages of social life development of the disabled citizens and the emergence of NGOs. This overview indicates the social movement of the disabled in Iran and NGOs has had a significant development, over the past two decades. There are two factors that persuade the development of NGOs. First is the inability of the role of government to supply the needs of the disabled which persuades them to seek support from NGOs. Second is the increasing attendance of the educated disabled and professionals in positions of management, office and social activities within the NGOs, who contribute to coping with problems and pathologies of such organizations (Moeini, 2011).
“Obstacles of NGOs in Iran:

1. Insufficient professional human resources.
2. Lack of professional structure. Many of the organizations for the disabled in Iran lack professionalism in both structure and services.
3. Lack of financial stability.
4. Lack of democratic succession of management.
5. Lack of executive procedures and methods for inspection.
6. Dependence of most institutions on government budgets.
7. The anomalous control of the government over DNGO.
8. Lack of national linking channels”. (Moeini, 2011, p64).

This study is an overview about the recent situation of disabled people in Iran and role of government and NGOs about this group. This study contributes my study in explaining the situation of RP patients and their limitations in demanding their rights and needs through communities and NGOs.

# Chapter 3:

# Theoretical Framework:

In this chapter theories are categorized on the basis of three Micro, Mezzo and Macro levels. I have focused on generalized theories like stigma theory in micro level which have explained RP patient's individual barrier and personal coping. In mezzo level, I focused on coping on social support theories to describe family and friends reactions to RP patients and RP patient's participation in the community. Finally, Macro level is described by dynamics of power by Foucault and social oppression theory of Oliver.

The barriers and Challenges which RP patients are experiencing in Micro level in their individual life is explained and discussed by generalized other concepts of Herbert Mead, stigma theory of Erving guff man and coping theory.

## 3.1.Stigma Theory

Erving Goffman has raised stigma theory. He outlined that stigma has different kinds including abominations of the various kind of body deformities, blemishes of individual character, tribal stigma of race, nation and religion. Stigma, ego identity, social identity and the politics of identity might be the most suitable concepts in indicating the picture of RP patient's individual barriers in Micro level.

A stigma is the specific kind of relationship between attribute and stereotype. One type of stigma is abomination of physical deformities. Normal people can stigmatize a person by their attitude. Normal people deem that the persons with stigma are not human beings. According to this assumption, varieties of discrimination are practiced, through which the person often loses their life chances. Stigma theory is an ideology to clarify the degradation of the stigmatized person and account for the danger they indicate. it seems generally true that members of a social category may strongly support a standard of judgment that they and others agree does not directly apply to them. (Goffman, 1963, p.14)

### Ego identity:

Ego identity is an arena of argument and discussion about what the stigmatized individual ought to think of himself. (Goffman, 1963, p.150)

### Social identity:

Our social identity is what others understand about us by virtue of the groups to which we belong. (Goffman, 1963, p.150)

### The Politics of Identity:

Goffman introduced the term 'The politics of identity' to characterize the interactions between the stigmatized, the 'normal' and the 'own' (who understand the world of the stigmatized without being stigmatized themselves). (Goffman,1963.p149)

RP patients were stigmatized by others behavior which is a consequence of the social situation of RP patients in Sweden and Iran and could be easily described by stigma theory and its concepts. Ego identity is a suitable concept which indicated self-image of RP people about themselves in this study. Furthermore, Social identity presented the ordinary people's dealing with RP patients with specific norms. These norms might enforce some ideal definition about normality and on the other hand, stigmatized groups of people with differences as abnormal. These stigmatized behaviors could affect RP people's life in different aspects. RP patient might deal with stigmatization in family interactions, friend interaction. Stigma theory is interrelated to social support theory by influencing RP patient's access to social support through family and friend interactions.

I have chosen stigma theory to analyze personal challenges of RP patients in Iran and Sweden. There are key concepts in this theory which were used for analyzing the process of their stigma. These key concepts include ego identity, social identity and identity politics. Social identity and ego identity are interconnected and influence each other. I believe that Social identity is socialized, internalized and shaped by norms which are adverted, taught and practiced through mass media, school, and university and in family member's interactions, peer groups and public places. There are dominant norms which are socializing from Macro powers such as authorities, policy makers and service providers. Thus, I found out a relation between macro level and micro level through transferring norms from authorities to individuals. These norms could be limiting and disregarding all the disabled people of society with different disabilities. These norms can make limitation, stigmatization and exclusion for different people specifically RP patients with specific visual impairment. RP patients stigmatization occurs by generalized others; ordinary people and stigmatized RP patients with generalized others. In fact, Generalized others are norms which are internalizing in society.

### 3.2.Self-theory:

Herbert Mead has raised self-theory which contains various concepts but I have utilized some concepts selectively such as Generalized others and self.

Organized attitudes which are common to specific groups in the society make up the organized self. Through self-theory, a person is a personality through their belongings to a community; the individual possesses a self just in relation to other members of the social group. The Self structure indicates the patterns of general behavior of its social group. He outlined that, however the individual is a citizen with civil rights; he is a member of community and has duties. In his idea, the individual reacts to this community to change it. Moreover, he emphasized that, the individual not only has rights, but he has duties, he is not only a citizen, a member of the community, but he is one who reacts to this community and in his reaction to it, changes it. The "I" is the response of the individual to the belief of the community. His response to that organized attitude, changes it. He defined "I" as individual response of person to the organized attitude of community. (Mead, 1934, p.135)

### Generalized others:

Mead defines his concept which is called "generalized other" as an organized and generalized opinion of a social group. The individual determines his or her own behavior according to the generalized viewpoint of the social group. (http://sociology.about.com/od/Profiles/p/George-Herbert-Mead.html)

### 3.3.Social Support theory:

"Social support is the subjective feeling of belonging, of being accepted, of being loved, of being needed, all for oneself and not for what one can do". (Moss, 1973) Social support is defined as a process of evoking resources inserted in social ties to fulfill instrumental and expressive needs (functional needs). Social support is significant in terms of expressive and instrumental needs. According to expressive needs, ego wants to have access to someone who can share, understand and sympathize with his or her feelings. Process of Social support contains three parts: Action/message, interaction and relationship. Supportive actions and messages are made within the interaction. Social support can be specified as support seeking, support providing and support receiving. (Moss, 1973)

Thoits determined social support as coping assistance. She mentions that coping and social support have various functions in common. These functions comprise instrumental functions, emotional functions and perceptional functions. Instrumental functions in social support contain assistance and help, and in coping they comprise problem focused coping. Emotional functions in social support consist emotional support and in coping they contain emotion focused coping. Perceptional support in social support comprises informational support that modifies conceptions of meaningful aspects of stressful situations and in coping it contains cognitive restructuring. The effectiveness of social support as coping assistance relies upon on a compatibility between the need of social support seeker and the resources of the social support provider and skill. (Eckenrode, 1991, p.248)

### 3.4.Coping:

Coping is defined as changing cognitive and behavioral efforts to manage specific claims that are assessed as transcending the resources of the person. This definition includes three important characteristics:

-It is process oriented.

-Coping relates to what the person actually thinks or does within a specific context.

-Coping is defined by personal tendencies and persons assessment of the demands of a specific situation.

The contextual approach emphasizes specific stressful situation as opposed to general stressful situations. Coping has two major functions:

Problem focused coping is defined as a way of dealing with distress by managing and changing the problem.

Emotional focused coping is described by modulating emotional responses to the problem.

Problem focused forms of coping are applied for the situations which is changeable whereas emotion focused forms of coping are relied upon more when situations are unchangeable. Problem focused coping have various forms such as cognitive problem solving and decision making, interpersonal conflict resolution, information gatherings, advice seeking, time management and goal setting. Emotion focused forms of coping include cognitive efforts that modify the meaning of a situation without changing the environment by using techniques such as cognitive reframing and looking on the bright side of things; behavioral efforts to make oneself feel better. Problem focused forms of coping and emotional focused forms of coping can be mutually helpful. (Eckenrode, 1991)

RP challenges and life situation of RP patients in Mezzo level such as family and friends reactions and how RP affects these relationships is mostly analyzed by social support concept and coping concept with contribution of stigma and self-theories. Some concepts such as generalized others, self, social support indicate a good picture of RP patient's coping process in family and friendship relationships through living with RP.

### 3.5. Community:

Community and social network concepts have been applied to analyze the relation and influences of community and social network impact on RP people's life conditions.

Twelvetrees, 2008, has mentioned that community work is the process of helping ordinary people to improve their own communities by initiating collective action. Community work has been particularly referred to the needs of groups who are disadvantaged or oppressed by poverty and discrimination on the base of class, gender, race, age, sexuality or disability (Adams, Dominelli&Payne,2002,p.130).Furthermore Henderson and Thomas emphasized that community work is interconnected with social capital, civil society, capacity building, and social inclusion. Thus, they claimed that local communities need to be supported to escape from isolation and marginalization in order to be connected with resources in society. (Payne, 2005)

I considered Community as a social resource where RP people can increase their network through their participation in RP community; Community might be the environment which increases social integration of stigmatized and marginalized groups of society such as RP patients. Community is a social resource which can facilitate people's inclusion by increasing their social interaction and increase their knowledge and acceptance. Community could work in three levels of increasing social acceptance of RP people.

### 3.6. Social Oppression Theory

Social oppression theory of Mike Oliver has been chosen to focus on all parts of macro level such as discrimination and exclusion through dealing with ordinary people in public places and work places, structural problems, social services. Social oppression theory has an obvious explanation to indicate the life condition of RP people and the shortages and accesses in the macro level.

According to social oppression theory, disabled people are being oppressed by being isolated and excluded from full participation in society. Oliver has outlined the distinction between the physical impairment and the social situation. Impairment specified as damaged organ or lacking of one organ or part of it, whereas disability is the impediment of activity caused by a current social organization which does not consider people with physical impairment. Therefore, they are excluded from participation in most of social activities. Hence, physical disability is a specific form of social oppression. Oliver outlined that social oppression theory's aim is to remove social injustice instead of correcting individuals. Regarding to social oppression theory, disabled people are certified as collective victims of ignorant society and described disablement as a result of social oppression. Social oppression contains personal prejudice, inaccessible public buildings and public transportation systems, separated education and exclusionary work place. Indeed, disabled people have been experiencing institutionalized discrimination which is the consequence of these social restrictions. (Barnes,Oliver & Barton; 2002,p.38) (http://whatsortsofpeople.wordpress.com/2008/08/15/the-personal-tragedy-theory-of-disability-mike-oliver-and-the-social-model/)

Oliver has outlined that social change and barrier removal might be possible by political empowerment of disabled people as groups. Social model of oppression theory gave the priority to social change instead of individualized treatments, medical interventions and establishment of politicians and policy makers. (Barnes, Oliver & Barton; 2002)

### 3.7.Dynamics of power

Foucault indicated society as a multiplicity of field forces which have connections. He focuses specifically on the organization of power relations. He emphasized on how power relations take forms and which techniques they are dependent on. Thus his concern is about structural relationships, institutions, strategies and techniques. He also outlined that power produces subjects. He highlighted that power produces subjects which are normalized to adhere norms of sanity, health, sexuality and propriety. He asserts that social norms shape the individuals in other word; norms are inscribed on their bodies. He defines the Govermentality as a way to administer populations done by authorities through shaping individuals in processes. Power can extend with the social body. No liberty exists between the meshes of the liberty network and since each way of life has its own characteristics, no one can judge about the ways of life. (Lukes, 2005, p.91)

There is always a resistance which follows power. Totality of practices makes it possible for individuals to constitute, define, organize and instrumentalize the strategies to apply in individual's life. He outlines that socialization of individuals has occurred through orientation of roles and practices that are given culturally and socially. Oppression is the outcome of regulation, disciplines and controls. This socialization could be seen as a wider form of governing out of state which is done by employers, administrative authorities, social workers, parents, teachers, medical personnel and all other experts. These authorities offer and impose these roles and practices to individuals. He highlighted that power relations are not monolithic and they always produce new forms of culture and subjectivity. Transition of dominant forms and institutions can also take place through conformity to dominant norms. (Lukes, 2005)

Dynamics and organization of Powers have been applied to indicate the causes of stigmatization of RP patients through Socialization process of people with specific norms by various powers and their relationship.

# Chapter Four:

# Methodology:

This research is based on comparative qualitative study to raise the challenges of RP patients regarding the three levels of their life and the relation of these levels through living with RP in two different contexts of Sweden and Iran, in order to contribute in improvement of RP patients' life conditions and reducing their difficulties. This study is mostly provided for raising attention of academicians, professionals, authorities and RP patients about the RP patients' challenges in three levels of their life; Micro, Mezzo and Macro and the main role of these levels in decreasing the social oppression of this group.

Fifteen interviews were conducted to RP patients from Iran and Sweden. Five respondents lived in Iran and ten, in Sweden. Three respondents were services providers; an Ophthalmologist, a social worker and an eye pedagogue. Semi structured interviews were applied (Gilbert, 2008). The respondents were free to choose the day and place of their interview. Each interview took about 90 minutes in average. Face to face interviews with Swedish respondents were conducted in different places such as university cafe, restaurant, their houses and their work places. Snow ball sampling has been conducted to sample respondents. Through snow ball sampling researcher asks a participants to introduce other interested people with the same characteristics to participate in study. The nominated participants are interviewed and asked to recognize alternative sample members. (Gilbert, 2008) According to difficulties to find and access to RP patients in two contexts, snow ball sampling has been the best and the cheapest way of sampling in this study. The involved respondents belonged to the age group of 18 to 47. Interviews of the Iranian respondents were translated from Persian to English and one of the interviews with a Swedish respondent who could not speak English was translated by a native Swedish person to English language. Hence, other interviews have been conducted in English. All interviews were transcribed in detail. Gender equality was observed through respondents' participation in this study. Interviews took place in quiet settings. I recorded the interviews with the Swedish respondents by MP3 recorder and transcribed them in detail. Iranian Social policy for people with disability has been translated from Persian to English.

## 4.1.Advantages of Semi Structured Interviews

Semi structured interviews were conducted. Semi structured interviews provided opportunities for respondents to express their problems freely and with more details, so respondents have no limitation to transfer their challenges to researcher and also. In addition, the researcher has more possibilities to show a clear picture of recent life conditions and challenges of the interviewees. Through elaborated data gained from the interviews, I had more information to

indicate similarities and differences; therefore I could compare differences of life conditions of RP patients in various social contexts. All interviews were conducted by interview guide. Semi structured interviews were applied to explore deeply into the research topic. Respondents from both countries were very responsive and had an active role in cooperating in this research. Moreover, respondents had the opportunity to talk about their challenges, deeply and in detail. The interviewer can probe areas which are expressed by respondent's answers; hence, the interviewer might be able to pick up information that has not been raised in question guide. (Corbetta, 2003)

## 4.2.Difficulties through collecting data:

Finding the Iranian respondents through their vague and unknown network was the most difficult part of my study. Additionally, some potential respondents refused to participate in this study considering their critical social situation in Iran. Moreover, I did not have any access to professionals working in RP field in Iran. Since I did not have any access to equipped mobile phone which could record long time interviews, also inaccessibility of interviewees to suitable internet facilities, made me to perform all interviews by expensive phone calls from Iran which were recorded by respondents, and then sent by my family members to me. Furthermore, I dealt with lots of disconnections through phone calls which increased the expenses of communications. Due to two hours and thirty minutes time difference between Sweden and Iran, arrangement of appointments with the Iranian respondents was quite difficult and time consuming. Furthermore, considering the inaccessibility of Iranian respondents to safe public transport, my friends and family members collected all the recorded interviews in Tehran and sent them to me by e-mail. Some Swedish respondents had difficulties to express themselves in English.

## 4.3.Methods of analysis:

Content analysis has been utilized as the method of analysis. Findings were analyzed according to three levels of RP patient’s life containing Micro, Mezzo and Macro levels. Micro level was analyzed by Stigma theory and self-theory of Herbert Mead. Mezzo level was analyzed by coping theory, social support theory and community concept. Macro level was analyzed by power theory of Foucault and Social oppression theory of Mike Oliver. Conceptual analysis which is a type of content analysis has been used for data analysis. I categorized and analyzed the data with main items according to research questions (Kvale & Brinkmann, 2008). Moreover; I have not separated three levels of Micro, Mezzo and Macro through analysis and discussion according to the interconnection between them.

## 4.4.Validation:

Validation investigates that how the researcher have followed the research questions during collecting data and analysis.Furthermore,Validation considers the management of researcher in observing balance and harmony in all parts of research (Kvale & Brinkmann, 2008.p248). Question guide, interviews and analysis have been performed and categorized on the basis of research questions. Three levels of Micro, Mezzo and Macro have been followed as the main themes with their sub themes in the whole findings, theoretical part and analysis according to research questions.

## 4.5.Generalization:

**Analytical generalization** involves a reasoned judgment about the extent to which the findings of one study can be used as a guide to what might occur in another situation.it is based on an analysis of the similarities of the two situations”. (Kvale&Brinkmann, 2008. p262). Analytical generalization can be utilized in this study according to similar findings and results which were achieved about two contexts of Iran and Sweden.

## 4.6.Ethical Considerations:

Informant consent and confidentiality of participants was greatly considered in this study. Through informant consent, the nominated participants have freedom to decide for participating in research activity.(Gilbert,2008) Based on confidentiality, data collection was conducted for academic purposes and individual’s identification, and privacy will be protected and not be disclosed in the transcription and analysis (Gilbert, 2008).

# Chapter 5:

# Findings and Analysis:

This chapter presents the findings, personal comments and analyses of the topic of my dissertation. Findings and analyses are categorized by specific items. Each item is based on research questions. Findings and analyses are based on three Micro, Mezzo and Macro levels. Micro level discusses mainly about individual barriers and personal reactions of RP patients in Sweden and Iran. These items were analyzed with stigma theory and self-theory. In Mezzo level, family and friends' support is defined as social support that RP patients usually gain and the respondents explained about the following topics:

- Reaction and acceptance of their family and friends through living with RP

- Participation of RP patients in formal and informal RP communities and finally
- The influence of such communities on their lives.

This level was analyzed by social support theory, coping theory and concept of community. On Macro level, the following topics are presented:

- The social exclusion and stigma that RP patients are usually dealing in social context,
- Public awareness about RP disease and RP patients,
- Their access to public transport and public buildings,
- Their access to social services specifically through living with RP,
- Evaluation of RP patients about the role of policy makers in improving the policies, plans and their enforcements.

This level was analyzed noticing Power theory, Stigma theory and Social Oppression Theory. Analysis contains the author's personal reflections and the comparison between the two countries, taken into accounts the similarities and differences. The analysis includes the author's personal comments by referring to theories and concepts and comparison is made between two propounded countries.

### 5.1.Symptoms of Retinitis Pigmentosa

In this part, respondents explained the process of their recognizing about physical symptoms of RP.

One of the Swedish respondents mentioned that:

*"I got RP when I was 2 years old. My parents are cousins, so this relationship could be the main reason of my disease. My sister is also an RP. I was 17 and my sister 20, when we first found out about our RP. It was in the year 2000. This means that we had this problem from the beginning, but it was not diagnosed. We were somehow neglected by parents and the medical society. We may have been misdiagnosed earlier or they an error occurred or the diagnosis was failed, but the case is that when we were young, I noticed I had no problem except the night vision. I was night blind but I had no other symptoms of RP. For instance I had no such problems like bad visual acuity, problems with a contrast sight, problems with sensitivity to light, problems with the visual field, etc. Therefore I may say that it is only in the recent 10 years that I have actually experienced problems of this kind so paradoxically when I received my diagnosis. My sight vision started to deteriorate. Yes, since then my vision has deteriorated. But I believe my parents try to deal with it and try to find information and solutions about it. We have discussed about RP so many times and we accepted it as a given fact. Of course it became a bit tougher and more difficult when I went to secondary school."*

One of the Swedish respondents underlined that:

*"I was born with RP and it is actually quite an interesting story. When I was born I did not react as one may expect from a baby. I could not see around. My parents did not figure out that I was visually impaired, during the first years. I did not react to movements. They thought I had some kind of brain damage so my parents were quite upset because they did not know what to do. Then they found out it was not like a special syndrome such as ADHD. When I was one year old my doctor said "I think she can't see". He diagnosed my visual impairment, then I got glasses. I developed my sight when I was one year old. When I was 14 years old when I was told that my visual impairment was going to develop. I tried not to think about it very often. I do not remember my situation when I was a child, but apparently I had quite a lot of difficulties during my childhood. When you are a child you only understand that there is a difference between you and others, but you do not know the difference exactly because you have never experienced the sight of a healthy person.*

Another RP patient outlined about RP characteristics:

*"When you have RP, the context is a very crucial matter; therefore the sight field which you see may differ between various contexts and may also differ from time to time. Sometime you can have a better sight in one situation and worse in another. This may depend on various reasons like stressfulness, and not enough sleeping. It may depend on the light condition and to the number of people around you, or the environmental conditions. It may also relate to the existent or absent sunlight. Even if the person is in the same place but their sight may differ from one situation to another. You perhaps see quite well in one occasion and then you may not be able to see because of the changed contextual*

*factors. Therefore it is very difficult for people to understand you. It is not easy to communicate the patients' situation to other people because of their unstable circumstances. For an RP patient, it seems that every day the person is a newly visual impaired. The RP's vision is not stable. It deteriorates and is affected by contextual factors, so this makes it a pedagogical impossibility to communicate this to other people. It all depends on how the person sees, for instance I can move around quite easily then I do not see many details, while for RPs, they have problems in moving around on their own, but perhaps they can see details because they still remain in visual equity, therefore it varies between people with RP".*

According to these statements, these respondents have dealt with wrong diagnosis in their childhood. Their RP intensified slowly and gradually. While, they have coped with unstable vision, their vision have been affected by environmental and contextual factors such as light condition, enough sleep, noisy crowd, night blind. Moreover, their vision loss increased while they were teenager. Generally, RP patients, dealing with difficulties in orienting and peripheral vision loss.

## 5.2. Individual Barriers

Micro level indicates individual barriers, coping and challenges of RP patients through living with RP. Respondent's individual barriers were various and mostly were the result of social obstacles in their society. Rather than (except that respondents are dealing with limited freedom in some activities through losing some parts of their vision such as reading and driving they are dealing with barriers which is a result of attitudes and lack of knowledge about visual impairment ,for instance experiencing unemployment and broken relationships and living without partner is a fruit of socialization in different levels of people's life such as mezzo and macro.

One of the Swedish respondents mentioned that **:**

*"The greatest barrier is in my life is doing my own life, to presume my own interests, to develop myself, regardless of what other people think and what other people do".*

As related to identity politics of Goffman, this patient is trying to manage the struggle between his ego identity and his social identity. He has utilized the problem solving focused coping by neglecting stigmatized norms and judgments of people about his RP. He is trying to manage his ego identity without interfering stigmatized social identity which he gained from prejudicing norms about RP. He believes that people's judgment might affect his individual life, therefore he is trying not to care about judgments and concentrating on his interests. (Goffman, 1963)

Another Swedish respondent outlined that:
*"I think there is a lack of understanding and a problem of communicating the situation and state of the RPs to other people, because it is impossible to make the people understand how complex it is".*
He believes that RP symptoms are potentially so complicated it would be too difficult for RP patients to transfer their difficulties through living with RP, to other people.
One of the Swedish respondents outlined that:
*"Because of RP, I do not have the freedom to do what I want to do. Everything is more difficult to do with RP. It takes longer time. For me, RP developed so rapidly since one year ago. I could read most of the things, but now everything is unclear and it is hard to read".*

Her physical limitations to do activities through living with RP are her individual barriers. So losing vision limits RP patients in their range of activities, and doing some activities are time consuming for them.
Another Swedish respondent highlighted that:
*"RP affects what I can do and what I am comfortable to do, I do not like to go to places where I know there are many people because I cannot see where to go, I cannot manage to be in gatherings. My visional field is less than 10 degrees. In crowded places I get very confused and dizzy, so I prefer to avoid going out. If I have someone to go with, and they can help me, it's ok, but I prefer to avoid big parties. .It's not always nice to ask for help. Can I take your arm? I do not always like to do that. I want to manage myself. It is about pride to not always ask people; your family may be no problem, but with your friends and others it is not very easy. In some way it has affected what I do".*

I have interpreted this, that in coping process, the respondents were trying to avoid asking for help, considering their ego identity that they have in their mind as an independent person that is applied for fully sighted people. Therefore they exclude themselves from social interaction and gatherings by avoiding to join them. These actions show that RP patients have been socialized by strong norms about independent person with specific characteristics. (Eckenrode, 1991)
One of the Swedish respondents stated about barriers which she is dealing in her life: *"When you use white cane, you can feel and observe the prejudices. Everyone believes that you are totally blind, so this is an example of prejudice and lack of knowledge. It is a very classic experience for the people who live with RP. The fact that people do not understand and do not believe you, for instance, when you are in a shop and ask for help or you ask for the direction to find an item, and if you do not have the white cane then people do not believe you. They may ask themselves why you ask such a question, because it seems that you see, but when you have the white cane and you can show them, they understand why you ask. So the main issue is lack of understanding, information*

*or knowledge about RP".*

I have realized that, public knowledge about visual impairment is defined by specific social appearance. Having sight loss means that visually impaired persons should carry white cane, to be able to get help from people. They should build a trust by their appearance in public places; otherwise people do not trust them as a person who deserves to be helped. So in my opinion , RP patients are dealing with another kind of exclusion and as a coping with this exclusion in public places, they avoid to ask for help from strangers or they are not comfortable to go to public places, therefore they will be more isolated and independent. These behaviors are the consequence of stigmatized social identity which is socialized by governors on different levels of society (Lukes, 2005).

Another respondent highlighted how RP affected her life style:
*"RP affects some parts of life strongly. It affects all the strengths and thoughts due to this problem. I cannot even think if living in countryside, because the public transport is not suitable for handicapped people. So if I want to be independent, I should forget about any entertainment (like travelling) and enjoyments. I considered RP as a weakness because I think about any limited possibilities, and right now I am pondering the work. I do not think that I can work as a preschool teacher and be retired in this job, because I have RP and my sight is gradually deteriorating and due to this, life becomes so difficult, and to do everything you have to consume lot of energy. I do not know how I can manage with the small kids in classes. You have to be very careful and focused".*

As I noticed, the respondent seeks a solution for coping with the environmental limitations by moving from countryside to the city. Furthermore, unstable visional situation of RP patients make it difficult for them to plan for the future. This unstable characteristic of RP about the gradual losing of the vision and the vision being affected by environmental factors, make the problem solving more complicated. (Eckenrode, 1991)

Two Iranian respondents emphasized that the problems for marriage was their main barrier in life and naturally they prefer to have a healthy partner without visual impairment. They argued that: term, fully sighted people cannot live with someone who has some kind of handicap. Socializing with stigmatized norms about being visually impaired people and focusing on their inabilities instead of their abilities, is the main reason of their problems to have partners. Therefore while experiencing these stigmatized social identity through living with RP, they would like to integrate with the society through living with healthy and fully sighted people. In their coping, they might try to decrease their stigmatized social identity but excluding other visually impaired people by not integrating with them. In conclusion, I realized that, RP respondents exclude each other as much as fully sighted people exclude them from their lives. (Goffman, 1963)

Iranian respondents mentioned their individual barriers regarding their labeling as disabled in work place, which affects them negatively, and brings about discriminatory behavior in their working environment and finally develops obstacles in using their potential abilities for performing their job and low chances in entering labor market as visually impaired people. Furthermore they have difficulties in getting married. They cannot find suitable jobs according to their education. One Iranian RP woman emphasized that as a woman it was more difficult for her to enter the labor market. She had also some difficulties for being accepted in the family and get married. She added that men have more opportunities to go to labor market because they have more chance to integrate with the society and finding more networks to find a job. Regarding social oppression theory, RP patients are dealing with prejudiced norms by employers and colleagues in Macro level. Furthermore, Iranian RP patients are experiencing double social oppression and exclusion, considering their gender. (Barnes, Oliver & Barton; 2002)

**Comparison:**

The Swedish respondents RP patients are dealing with the following problems:

- Time consuming activities,
- Limited freedom,
- Being judged by people,
- Loosing vision in short term,
- Difficulties in reading,
- Dizziness in crowded places,
- Being under prejudices when using white cane,
- Being under prejudices as visually impaired,
- Misunderstanding and lack of trust among people,
- Attitudinal and structural limitations,
- Difficulties in planning for the future,
- Difficulties to have access to public transport,
- Difficulties to have interaction with people,
- High probability of losing jobs as visually impaired people.

As regarded Iranian respondents, plus the above mentioned problems, they are facing the following problems as disabled people:

- They experience discriminatory behavior from their colleagues in their work environment,
- They cannot use their actual abilities in performing their job,
- Some respondents mentioned that they are not able to find suitable jobs according to their education, because of their low vision,

- They have communication problems due to their disability,
- They have problems for getting married,
- They do not have economic independency,
- They do not have the independency to access the public transport, liaisons and sports

Social opportunities can help respondents to apply problem solving reaction through their coping with social limitations. Iranian respondents, who have not been able to find jobs, usually sit at home, become isolated from the society and get more and more financially dependent on their families. In comparison with the Iranian respondents, the Swedish respondents mostly said that they have access to job coacher who supports them to find suitable jobs and the social security system provides them with a salary for volunteer activities according to their abilities (Eckenrode, 1991)

**Common barriers**

Respondents from both countries outlined that when they do not use white cane, people do not trust and believe to help them. Both Swedish and Iranian respondents are dealing with lack of close partnership. Swedish respondents mentioned that most of their love relationships get broken because of their RP and Iranian respondents said that they have a low chance to get married. Respondents from both countries deal with barriers which are mostly raised from their social context. Disregarding their physical barriers such as limitation in reading and driving, they are mostly dealing with barriers in integrating with the society, barriers such as getting employed, loosing job when they are already employed and difficulties to have close relationships.

Respondents from both countries outlined their unemployment and high probability of losing their jobs as their main individual barrier. According to findings of this research work, respondents are dealing with two types of obstacles in their work environment.

The Iranian respondents deal with two types of discrimination related to employment:

1- In spite of the fact that according to civil regulations, 5 % of existent jobs are allocated for the physically handicapped people, but in practice the law does not work for them, or, the 5 % of the existent jobs does not suffice the number of unemployed disabled people.

2- Most of the Iranian respondents said that they are not able to find suitable jobs according to their qualifications that they obtained before their visual impairment.

The Iranian unemployed RP respondents mentioned that they feel they are not productive citizens in the society and they are financially dependent on their families, a fact that reduces their freedom (Barnes, Oliver & Barton; 2002).

Some of them said that they are not able to use their abilities in their work place because of the dominant negative approach applied in their working environment about the people with visual impairment. According to this approach, RP people are disabled, therefore they should not (and cannot) do complicated works. In comparison, some Swedish respondents highlighted that they lost their job after losing and gradual deterioration of their vision, and some others are in the risk of losing their career in a near future due to deterioration of their vision, and they were worried about their job in the future.(Barnes, Oliver and Barton; 2002)

**Summary:**

RP respondents are dealing with physical barriers as consequences of RP symptoms. Moreover, they are coping with social barriers as the consequences of the stigmatized norms of both societies about being visually impaired, barriers like unemployment, not being able to be stable relationship or getting married, their difficulties in getting social support in public places when using white cane and avoiding to participate in friend's gatherings because of their unease and discomfort to ask for help.

### 5.3.Personal Strengths:

In this part, respondents have described their individual points of strength in coping with RP. I realized that stigmatized people are in interaction to manage the stigma and to find a balance. I have considered two types of copings as a reaction of RP respondents to cope and manage their emotional and social changes through living with RP. Therefore the respondents have an active reaction to their community by different types of coping. (Eckenrode, 1991)

One of the Swedish respondents highlighted his strengths through his RP **:**

*"I think you can have a good thinking school when you are an RP. I think you have to deal with inner thoughts and feelings which you can apply to other people, if you use it in a right way. You lose your vision but you can see other things. It is a choice. It is very philosophic. Salter has an existentialistic way for looking at your life. You have a bag but what you will put in it. Even if you have a problem you can use it. I mean it is your choice. I am trying to see myself in another people. The one who wears the shoes knows where the pain is ".*

This respondent has chosen a school of thinking as a way of coping with his RP.
I have realized that he used in his problem, solving focused coping. He is positive about his RP and he believes that he has active role through coping with RP.

Another Swedish RP patient mentioned that:

*"You step to a new, different life and of you have to do your best for everything. Maybe you have to change a little and change your life style, but some other things become more important, compared to the time when you did not have this*

*disability. On the other hand some issues get less important. You have to see it as not a big problem. I was very sad when I got the diagnosis. I was sitting at home, crying and feeling sorry for myself. Everything was so hard for me at that time, but then I realize I could not continue this way. I thought I must do something good about it. Your attitude about this issue is very important. In the beginning, I really thought that it was such a big problem, for instance I could not drive, but now I can do almost everything, maybe in another way, but I can do it . So, I started to appreciate it. At first you cannot see it like this but then you can really see it. When we help each other in this RP Group, I know that it's very good for me to contribute in this group. It is good for other people too; you get something from it yourself. You do other things in your life, gives you much back. You appreciate other things; I think you appreciate life in another way. When you get a disease you appreciate what you have. At first you just see what you do not have. I focused very much on what I did not see but now I focus very much on what I do see. I see and I can do almost everything, maybe sometimes it takes more time, but it is finally done. I can do it and if it is something I cannot do I should not focus too much on that. Do something else that you can do".*

I have noticed that, this respondent has reacted differently regarding experiencing his RP. First, she has coped emotionally, but then she has changed her coping to problem solving reaction by changing her attitude about her RP and life. Through problem solving reaction she appreciates her abilities in managing her life dependently. Regarding changing her attitudes about her abilities in present life, this indicates that she redefined her ego identity and as she stated, she has tried to make balance between her social identity and ego identity by participating in RP community and exchanging experiences between the group members. (Eckenrode, 1991)

Another Swedish woman also stated that:
*"I and my family could not accept my RP before joining RP Association. I could not explain my RP to my family".*

According to community concept and social support theory, RP community was a very influential factor for RP people in gaining social support from their families. Moreover, their participation in this community increased their individual acceptance. (Payne, 2005)

An Iranian RP patient outlined that:
*"Visiting my spiritual teacher who is teaching me yoga and doing collective and individual continuous meditation for more than 7 years, has been a turning point in my life. Now I am convinced about RP and the associated difficulties, through my knowledge about yoga and meditation. I am also very lucky because my family members are very supportive towards me. My mother companies me*

*wherever I like to go, she reads and records books for me. My brother takes me to mountain climbing and my friends try their best to take me to parties and young gatherings. My RP started when I was a university student in Computer Hardware course, and it developed gradually during the last 10 years".*

According to her statements, fortunately a lucky one, she has redefined her ego identity by using spiritual approach through practicing yoga and meditation. Moreover, her participation in collective meditations is a taking part in a community as a tool to integrate to the society and compensate the isolation that she is dealing in other aspects of her life. Moreover, I interpreted that doing meditation is her coping through living with RP. Meditation helps her to concentrate on her abilities instead her limitations. (Eckenrode, 1991)

**Comparison:**
Iranian respondents mostly did not find themselves positive regarding their reactions to RP, but they mentioned that they were inspired by other visually impaired successful people during visiting and participating in RP Association. Most of the Iranian respondents mentioned that they did not see any positive change in their life style. Only three of them believed that some positive changes occurred in their life style. In comparison, Swedish interviewees have different ways to cope and live with RP: Swedish respondents outlined unique ways of their dealing with their problem, for instance, one of respondents had an emotional coping such as crying, with her RP at first. One of them coped with his RP by applying his inner thoughts in other people and he mentioned that although he lost some parts of his vision but he could see things in other aspects (problem solving) and he also mentioned that it is the patient's choice to experience his life because no one can understand your pain without experiencing it. Some others stated that they have dealt with changes in their life style and they have gone through new steps in their lives. Some believed that they have changed the way of their thinking and attitudes about RP. They also believed that they appreciate their abilities although they were not able to do some activities they used to do before, but they emphasized that they focus on the things they can do. Altogether they were happy that they could manage their daily lives in another way. (Eckenrode, 1991)

### 5.4.Social network support:

In this part, the families' and friends' reaction towards the patients living with RP, as well as respondent's participation and idea about RP communities (Associations) will be discussed.

One of the Swedish respondents has outlined that:

*"My family did know it from the beginning, and therefore they did not know*

> *how to deal with it. We had no language for it. We had no way to talk about it. They are still left behind in one way. I have been helping them to understand it. I do not know if it is a Swedish mentality, but they had problem to express their feelings. I think they suffered about my problem. I could not help them; they could not help me neither. I and my father have not talked about it yet, about how it feels. Due to the situation, I naturally had some tough times especially about my father. Some girlfriends helped me a lot but now I have no partner. I have had quite a lot of relations which are broken up because of this disease, because it is quite problematic to live with someone who has RP. We have ups and downs. It can be tough to hang around with it. I think depression is connected to the disease. When it is dark I cannot see anything so my mind gets dark too. I have lots of pains and if you have someone near you they have to deal with it. When you get pain, people have to deal with it as well. That could be quite problematic in relationships".*

This respondent was dealing with the lack of knowledge of their family about RP. The unaccpetance of his family in long term affected his ego identity. It might be interpreted that, his family refusal to accept his disease made his social identity stigmatized and heterogeneous. Therefore difference between his social identity and ego identity in long term made him depressed. I guess that hiding his RP was an emotional reaction to dealing with his stigmatized identity in his family and among people. (Goffman, 1963)

Another RP gentleman stated that:
*"New things started to happen, people started to go out, parties, etc.. during the night time and I was a bit hesitant to do that, because I did not see in the dark , so I felt a bit strange. I had some severe hardship around that, since my vision has deteriorated quite repeatedly. Last year I become more and more confident in my own disability, I'm more aware of it now and I do not shy away from it. Earlier I was a bit afraid and scared to disclose it to other people. But now I'm not as sensitive as before, so I do not care what people think about me anymore, I did that of course when I was younger".*

I considered that this respondent had different ways of dealing, in the process of losing his vision through RP. When he did not lose a lot of his vision, he was more careful about stigmatized social personality that people had about him. He avoided to go out because he was embarrassed and ashamed about his vision, that indicates that his ego personality and social personality was socialized with stigmatized social norms about being visually impaired and he was trying to not being judged and his social identity did not appeared in social interactions. But during the time and with losing more vision gradually, he did not cope with RP emotionally. Dealing with stigmatized social identity made him to avoid social interactions (Goffman, 1963).

Another Swedish respondent highlighted that:
*"I do not know if I have accepted it. I won't accept that I'm going to be blind, I don't believe it. That will damage my career, maybe not severely but I cannot imagine how it is to be blind. I cannot imagine the transformation that I will face in my life. But I will try to cope with it as much as possible. Of course doing things take much more time when you are reading and engaging in different activities with the computer. It takes much more time that is the most problematic thing. When you live with this visual impairment you can do things very efficiently but sometimes they take a long time. I think I could use the possibilities for enabling myself to do things easier. I can utilize my abilities with the belief that "I can", then I will be able to utilize my potentials more and more, and in this case my life would be much more desirable. As I said I cannot accept the fully magnitude of visually impairment hence I do not utilize it as possible ".*

I realized that he could not accept the visual impairment as part of his personal identity. He has defined his plan for future disregarding his RP and he believed that he cannot practice his plan through losing his sight in the future. Moreover, his personal identity is influenced by his social identity. Regarding govermentality and Stigma theory, his social identity has socialized with the norms which are advertised in different levels like family level, among peer groups, school and mass media. (Goffman, 1963)

One of Swedish respondents indicated that:
*"I think my family realized that something was wrong, because when we were together in many places with many people, sometimes I was walking right into some person, sometimes I used to reacting a bit strange. They were of course a little sorry for me. I have difficulties in using public transport since I am living in the country side, so now I am dependent on my husband in commuting to my work place".*

Her family felt pity for her. This reaction is a consequence of stigmatized identity of RP people in Swedish social context. (Goffman, 1963). Moreover, she is dealing with exclusion in access to public transport which is a part of Social Oppression. She needs social support of her family. Therefore her freedom became more limited. (Barnes, Oliver & Barton, 2009)

One Swedish gentleman highlighted that:
*"We have a society of social infrastructures and when someone has problems, gets in between, which means your personal responsibility for other people is reduced. It means that cultural values allow someone to have pain because*

*according to social beliefs there must be a way to handle it. That makes a mentality. I have been thinking philosophically and after a while one understands that it is a door to open up and ask for help, because people want to help but in their own ways. People think it is a problem, but I am still dealing with it. Some part is related to me but there is another part that comes from outside of me".*

This respondent believes that getting social support from Swedish society is affected by the social welfare state. Strong role of social welfare state resulted less individual responsibility and sympathy of people towards each other. Considering govermentality concept, informal governors behave according to social welfare state functions. (Lukes, 2005) Furthermore, this respondent thinks that there are ways to open the door for gaining social support from people. I interpret that he has tried to make a balance between his social identity and his ego identity, and he was aware of his stigmatized and influenced ego identity by social norms. According to the concept of "I", he is trying to have a response to society and gaining help by his act in front of community.
(Goffman, 1963)
One of the Iranian respondents mentioned that:
*"In the university, I was ashamed when I fell down in front of people because then they realized that I had some visual impairment. Relatives did not know that I had visual impairment, and they used to complain when I fell down. So these reactions made me embarrassed. I do not usually talk to my family and friends about my RP".*

This respondent was coping with his RP, emotionally, which is the result of stigmatized social norms about being visually impaired and also the poor knowledge of the people about RP disease. It might be interpreted that stigmatized norms lead to mistreatments from his family members and friends. His emotional coping was ended to avoid in getting emotional support through avoiding social interactions and social gatherings. This Social segregation might decrease his individual acceptance of his RP. (Eckenrode, 1991)

One of Iranian respondents explained that:
*"My family members understand me, but sometimes my mother misunderstood me. It is not of course intentionally, but many times she told me are you blind? It is very disappointing and as an emotional subsequence I cry. Sometimes she forgets about my problems and behaves me as a healthy person. But my sister understands me deeply. She is so intelligent. She deals with my RP logically. She helped me to accept using white cane".*

I have interpreted that this woman has coped differently towards different reactions from her family. She had an emotional coping such as crying and despairs due to misunderstanding of her mother about her sight loss and she had a problem solving focused coping towards her sister's suggestions in using white cane. In conclusion, her individual acceptance about her RP is highly affected by her family's reactions to her. (Eckenrode, 1991)

One of Iranian respondents stated that:

*"Accepting me and my sister as RP patients is so hard for my parents. My mother was so emotional but my father was restricted. My father loves his healthy children more than us. When we have guests they hide us. I think my father did not accept this fact. There is a cultural poverty about visual impairment in Iran. Apart from being an RP, I have always suffered from cultural weaknesses and discriminated behaviors as a woman, which makes my problems double. They do not invite us for parties and family gatherings and my parents hide us from the people, so we are often isolated and lonely".*

I have noticed that social personality of visually impaired people is highly stigmatized among people. So these stigmatized norms about visually impaired people might influence their social identity and ego identity. Hiding and isolation of visually impaired people can influence their ego identity. The visually impaired children are easily and obviously discriminated at home. (Goffman, 1963)

Another respondent from Iran outlined that:

*"Before participating in RP Association, my parents thought that RP was a rare disease and they had a passive approach about it. I need help so I should adapt myself with the people and cooperate with them".*

**Comparison:**

Both Swedish and Iranian respondents have common situation regarding their families. Families have difficulties to accept their disease. RP Communities help the families to know the problem much better and those who participated in RP communities increased their acceptance rate. There are still some families who did not communicate with RP Association. Furthermore, Iranian women with RP are dealing with more discriminatory behavior in the family environment, compared with RP men. Compared to the men, it is more difficult for the women to be accepted in family gatherings as a person with visual impairment. Considering both Swedish and Iranian respondents the only organization which influences and increases the awareness and acceptance of family members of RP patients are RP associations and RP communities which indicates that other organizations act weakly in increasing the people's knowledge about this disease through schools, mass media such as TV and radio. I believe that low acceptance of families form dominant normative approach about disability in both Swedish and Iranian social context. Family members are socialized with norms which have inflexible and limited frame for acceptable citizens at home, at school, in media, etc… Family acceptance and support might facilitate the individual coping process. According to findings, refusing RP patients by family members made them feel depressed, disappointed, excluded and isolated.

**Friends' Reactions:**
In this part, RP patients explained about their friend's reactions and support. They also discussed about their tendencies in making friends with visually impaired people. Social support theory and Stigma theory were used for analysis, in this part.

One of the Swedish respondents explained about effects of RP on his social friendships:
*"It is difficult to take part in social gatherings and make friend with other people. One reason is that the RP cannot have eye contact with others. The RP people cannot control the environment around them. They do not know who is there. Therefore it has been quite a hard time for me since 6, 7 years ago when I realized about my RP. When I moved to Gothenburg I had more problems because I did not know so many people here. The gradual deterioration of my sight affected my social contacts greatly. Nowadays, I'm more confident but of course communicating with the people is still quite difficult for me. My friends think that I'm strange. They cannot easily distinguish when I need help because of dynamic changes in my vision".*

The respondent believed that having no eye contact and having low self-confidence about one's vision has affected his friendships. Moreover, having low vision decreases the person's control of the surrounding environment and recognition of people there. It may be concluded that low vision might decrease RP people's social network potentially. I have interpreted that lack of knowledge of the public could affect the RPs and exclude them from their friendships. The complex dynamic situation of their vision affects them to gain social support. (Eckenrode, 1991)
Some Swedish respondents mentioned that they feel excluded in their friend groups because they do not call them for going out, some others believe that it is hard for them to be accepted in group friends. They also highlighted that they cannot participate in all friend's gathering because they do not feel comfortable to ask for help and get support from their friends. According to these statements, Swedish RP patients cannot fully participate in social interaction among their friends. Their friends have shown the stigmatized social identity of RP people by excluding them from gatherings. (Goffman, 1963)
Another Iranian respondent stated that:
*"I do not like to have friendship with the people who have visual impairment because they have individual, behavioral and social problems such as the way of their clothing, way of talking. They have problems in reactions. But I enjoy some blind people. I'm a flexible person. I can adapt my behavior according to the*

*situation".*

The two professionals have mentioned their ideas about social support practices among families and friends according to norms in the Swedish social context: *"We have big demands and pressures in our social life. You should be very independent, effective and deal with everything yourself. As RPs, we should be good husbands, wives and parents .I guess in your country at least you have a very good social net. Then you got your help from there (family) but this was destroyed in Sweden in the beginning of 1990. We are very lonely in Sweden. It is a big pressure on the individuals. Everybody is taking care of themselves .Even if you are healthy you have to be on your own. It is not a big difference between being able or disabled. .If you do not have good people around you, it is up to you. You can be more helpless when you have a disease. We do have a good social security system compared to other countries, but in the same time people think that the state would take care of everybody including RPs and they should not bother themselves. It is also about individuals, and what types of people are around you and what type of people you meet. The major issue is meeting. If you have strength to deal with the disease you will ask more helps from others".*

**Comparison**:

Swedish respondents mostly believed that RP affected their friendships negatively. They pointed out that having eye contact could affect people's relationships and they mentioned that they have lower chance in keeping their friends and finding new friends when they lose vision. Some other found it difficult to be accepted in friend groups as an RP. They also feel uncomfortable to join friends gathering because of their difficulties to ask for help and some mentioned that they feel excluded from friends gathering. Some others mentioned that they felt helpless from their friends considering reduced individual responsibility toward others' problems. In comparison, Iranian respondents mentioned that they did not join their friends' gatherings because of hiding their low vision. Some others do not join friends' gathering because they believe that they cannot enjoy shared activities which they used to have before their RP. Respondents from both countries did not have any RP or visually impaired friends because of lack of interest of the healthy people in communicating with visually impaired people.

**Common challenges**:

Social norms and stigmatized social identity of visual impaired people isolate them and makes some obstacles for them to participate in society. Public awareness and social norms about being visually impaired affect their social life. (Goffman, 1963)

## 5.5.RP Community (formal and informal):

In this part, interviewees have explained about their participation in RP community. Furthermore, regarding interviews with professionals in an eye clinic in Sweden, they mentioned that RP patients can use their services through apothomologist's introduction letter, and through their treatment process they will be introduced to RP Association and SRF[2]. This indicates that medical health care system has a power to facilitate the interaction between RP respondents, RP Association (community) and health care administration. In comparison, the Iranian respondents who were active in RP Association mentioned that Iranian RP Association claimed that they cannot rely on official statistics about RP patients and they estimated that there are 70000 RP patients in Iran, but because of the communication gap between patients and communities they could only recognize and register 4000 RP patients all over Iran. There is segregation between patients, RP community and medical networks. More over the Iranian respondents mentioned that RP Association only has a medical approach to the RP community and they mostly have informal communities and networks through some NGOs that provide services for visually impaired people.

**Iran**:

Most of the Iranian respondents thought that joining the RP Association was very useful for them. It increased their knowledge about RP, as well as their individual and family acceptance by mingling with other RP patients. Through the RP Association, the RPs have met some RP patients who are successful in their academic and career life and meeting these people was very inspiring for them. Some respondents found RP Association as a social network, for instance, they communicated with other private institutions that provide many services and activities for visually impaired people. Some respondents mentioned that they had passive approach about their disease before joining the RP Association. Some of the respondents were registered in this Association but they do not believe on these activities and community work in Iran, so they do not participate in meetings and activities. One of the respondents believed that there was a lack of teamwork in the RP Association in Iran. (Adams, Dominelli & Payne, 2009)

One of the Iranian respondents mentioned:

*"My father found the RP Association. He encouraged me and provided opportunities for me to participate in their gatherings. Founder and headmaster of this Association who is RP herself is a very successful person both in her professional and individual life. She inspired me and my family. I found many people in the Association and I realized that my educational and social life is more satisfactory compared to them. Some of them could not even complete*

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[2] Synskadades Riksforbund: Association of Visually Impaired People in Sweden

*their education even at high school level. I found very good friends in this Association. So these friends made me change my life style. Then I learned Braille[3] and orientation, and used white cane, so I found new communications. These new friends made me more independent and caused to know my abilities.*"

**Sweden:**

One of the respondents said that they avoided to participate in RP Association activities and meetings because he believed that meeting with RP patients makes him to go through his disease and think about it more. One of the respondents is a founder of RP Association and she believes that their activities are so inspiring, increasing knowledge and awareness about RP. Another respondent believes that it is important to participate in RP Association:

*"I think that in these communities you can discuss about RP and how to deal with it. I was participating in RP group which is hold by eye clinic."*

I have noticed that RP patients have had different ways of coping about their participation in RP community. Inactive groups had an emotional coping and active respondents had problem solving focused coping through their idea about participation in RP Association. (Eckenrode, 1991)

One of the Swedish respondents mentioned that:

*"I have found some good RP friends in the RP Association. It is a very good to have an RP Association because before I join the Association I felt very lonely. I had never heard about RP association before. I was just reading some texts in the internet, and I found RP Association. There are quarterly meetings in the Swedish RP Association. I myself established a group here in Gothenburg because I did not like the activities centralization in Stockholm. Now the Association in Gothenburg has 50 members. The group in Gothenburg is a form of self-help group. The function is that the members of the group with the same problem can meet each other and we can talk about our common barriers and difficulties. I am very relaxed with the group members, because I feel confident there. I know that there would be no problem if I fall down or get through some persons. Getting support from the people with common problems is an important issue. To me it is even more important than support from doctors and medical staff, because the doctors know what the disease is, but they do not know how to live with the disease. I am inspired through meeting the new successful people and I am learning from other RP members of community. My life style has changed a lot through my new communications.*

**The Author's Reflections**:

Some Iranian respondents mentioned that through these communities they found

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[3] Braille is a tactile writing system used by the blind and usually impaired people

new friends and private organizations. These organizations provide different services such as computer courses and access to audio books, in cheap prices. Through these facilities, the RPs are able to increase their individual and family acceptance. They can also increase their individual skills by learning new activities through participation in different courses and increasing their chance to find suitable jobs by social networks. (Adams, Dominelli & Payne, 2009)
Although RP community could be very useful in changing and improving the life situation of RP patients, but it seems that RP Association in Iran has only a medical approach towards this problem. Therefore, there is no self-help group focusing on social and individual life of RPs. The Association has usually informal meetings in private organizations which provide services for visually impaired people. (Such as charities). I found that, respondents have two kinds of coping through their participation in RP community. They compare themselves with other RP members in two ways. They are inspired about successful people and they appreciate their facilities and abilities compared to RP members with lower education level and lower vision.( Eckenrode,1991)

**Common social support:**

According to definition of perceptional support which is mentioned in the theoretical chapter, RP respondents from both countries got perceptional support from their participation in RP communities. For instance, they changed their perceptions about dealing with RP by getting informational support. They got informational support through exchanging their experiences and knowledge about RP disease in RP communities.

One social worker and one eye pedagogue who work with RP patients in one eye clinic in Gothenburg mentioned about their RP group:

*"We usually have some groups that RPs can enter and participate in them. Patients with different diagnosis can enter the group. Group includes 10 people. We meet once a week and these group meetings continue for 10 weeks. Here the patients meet ophthalmologist and learn to adapt with white cane. We have lots of discussions that patients have the opportunity to take part and talk about their difficulties and exchange their experiences, thoughts and feelings. They really appreciate it because it is very important to meet other people with the same situation. We recognized that meeting other people in the same situation is a big comfort that makes it easier for patients to go forward, so we have a lot of groups. They can listen and realize how to work with white cane. It usually takes a long time for patients to accept using white cane. In the beginning, they do not want to use white cane because using white cane means that they accepted their disability and then they have to motivate again and again. The most important thing is that they can meet others and they can see they use the cane and they get more motivated. They also can talk to me individually to try to go forward. They can put words on their feelings and to be able to handle it. The more they can express their feelings and their thoughts, the more they would be able to*

*handle the situation in the groups and our discussions. In September we will start to continue these groups for 3 weeks here. They can come here every day after work or after school. In these gatherings, they can cook food, go to the store, and do shopping. Not everyone goes further after joining these 10 weeks groups. They want something more; they want us to offer something more. SRF has also some groups, so they can continue within SRF. Because we can take care of everyone, we should let them go. One day they have to go to the society on their own. But we are always here to provide comfort and ease for them".*

**Comparison:**

Both Iranian and Swedish respondents have positive and negative ideas about participating in RP associations. Those with positive approaches have common reasons. They believe that participation in RP community can increase their knowledge about RP and they learn how to deal with it in daily life. More over by participating in this community they have the opportunity to talk about their experiences and share their ideas. They can learn from each other and focus on their abilities. They also mentioned that, their participation changes their families approach about RP and they did not see RP as a rare, strange disease. They realized that RP is not a big problem in their life. But those with negative approaches about participation in RP community do not have common ideas. Swedish respondents avoid participating in these communities because having more communication with RP patients make them to go through the RP and to think more about RP. Iranian respondents mentioned that they do not believe in community work in Iran because there is no integration among people. The negative approaches altogether believe that these activities are not able to help.

## 5.6.Personal Participation for Situation Improvement:

In this part, respondents were asked to explain their individual role to improve the living conditions of the people with this disability. I have analyzed this part by using power theory of Foucault and social oppression approach of Mike Oliver.

One of the Swedish respondents believed that she would like to work through changing attitudes and raising awareness. She mentioned:

*"I have established the RP Associations as an example of a cooperating tool for the disabled people to improve their lives. She also mentioned that: "If you think much about your own disability it would be easy for you to accept it and to think of other people with different types of disabilities. I think it is good to cooperate with people with different impairments. Society should not think that having disability is a big deal. Maybe that is what we can do to help others with disability. As an example that we established RP association is to increase people's knowledge about RP."*

She believed that by interacting with other RP people in their communities and sharing experiences, she can improve others. She is already a founder of RP community. It might be noticed that her solution through using problem solving focused coping is foundation of RP association and exchanging knowledge through this community. (Eckenrode, 1991)

One of Swedish respondents stated that:*”Actually I’m trying to do it through my theatre. We talk about important things, about human beings. I mean it in various angles. My emotions come from who I am. So I am a person with this disease of course, and I use my disease and experiences, to relieve it. The inner part of the people, he feelings, emotions and thoughts of are not very different, no matter .you are without arms, eyes, etc.. And if you try, you can understand another person’s points of view and if anybody starts to think like that, then structures start to changes and I think it can be done in other ways”.*

This respondent attempted to decrease this social oppression by communicating and increasing public awareness through his profession as actor. His strong point was that he put efforts to change attitudes and values through showing his emotions in the theatre. I believe that he was trying to provide opportunity for people to experience the situation of disabled people through playing. (Adams, Dominelli & Payne, 2009)

One of the Swedish respondents mentioned that: *“Changing the attitudes, changing in structures those two, I cannot come up with specific concrete measures right now. But it’s very important to raise awareness. I cannot act as professional, but it’s a continuous ongoing work".*

Swedish respondents perform many different activities to improve life conditions of disabled people. Some of them limited their responsibilities since they relied on the disabled’s family members. But most of other Swedish respondents believe that they are responsible about this issue and they gain this aim by different activities such as establishing RP association, raising awareness about disability e.g. in their daily job and finally in participation through RP community.(Eckenrode,1991)

**Iran:**

One of the Iranian respondents emphasized that she has written a book about RP and she believes that increasing information by team work is necessary to improve their life condition but she also believes that in order to enforce and improve social policies in Iranian context one needs to have a high social position in society to establish some contacts, otherwise disable people are voiceless.(Lukes, 2005)

This respondent underlined that: *”Improving life conditions of disabled people is possible through increasing public awareness. She suggested to publish books and doing team work, but she also mentioned that improving and enforcing social policies about disability is impossible without having high social position* *in the government. She added that by using one's social positions you can have voice through your networks, which means these networks and your position can help you to communicate with policy makers in macro level. Indeed ordinary disabled people cannot communicate and discuss for their rights, without high position".*

Her statement indicates that she has individual freedom and opportunity to improve her life conditions by publications and books, but she believes that there is no opportunity for ordinary people to fight for their rights. I have interpreted that, there is no balance in power distribution among authorities, service providers and service users in Iranian context.(Lukes,2005)
One of the respondents outlined that: *"I think the disabled and RPs can raise knowledge of the people through going to the public places, like buses, subway etc…, using white cane, even if they are not quite independent in these activities".*

This respondent found herself active and effective by utilizing problem solving traction. She believes that it is possible to increase public awareness by individual action and interaction with ordinary people in public places. Thus it can be noticed that micro level could have an impact on macro level by individual acts. (Eckenrode, 1991)
An Iranian woman stated that: *"I have been suffering from being helpless in my society. We have no voice. We need to have international voice. I have to fight for all discriminatory behaviors. I have some limitations, but I am able. I try to increase the culture and knowledge about visual about disabled people. I want to change the people's idea about visually impaired people. In the same time changing people's idea is quite hard, it needs a long time and the people should also have a will to change their idea".*

She is hopeless about individual action in improving the life conditions of disabled people. She believes that Iranian disabled society needs international activists who can transfer their voice through their wide network. She also outlined that increasing public knowledge and awareness about disabled people and their social rights depends on cooperation of ordinary people as well. I have interpreted that changing norms needs public cooperation. (Adams, Dominelli & Payne, 2009)
Some other RP patients from Iran mentioned that*: "I have tried a lot to increase the social network between RP patients (70000) but just 3000 people are registered because we do not have any integration in our context and this is due to the structure of Iranian society. Social network is weak. The only help that I can do is to transfer information among people in our social network and sometimes I support my RP friends emotionally".*

Half of the Iranian respondents did not find themselves effective in participation to improve life situation of the disable people. These respondents believe that they do not have an open environment and enough opportunities to improve the situation and some of them do not have any interest in participate. Half of them recognized themselves as activists in improving the situation. They have different activities to achieve this aim. Some of them believe that they can be effective by attending in public places and having interaction with people. Some others achieve the same goal by participating in RP association and some by writing and publishing books about RPs and the discrimination applied to the them in order to increase the knowledge of the public.

**Comparison:**

Comparison between two countries indicated that in practice, Swedish respondents have more chances to change the situation. In contrast, Iranian respondents have two different reactions:

-Inactive respondents were hopeless about being effective in changing the situation, considering political, social and economic obstacles, within the Iranian context

- Active groups still believed that they can be effective to change the situation personally by daily interaction.

Respondents from both countries were active in improving life condition of disabled people through increasing public awareness of both RPs and non RP people in different ways. These options indicated that RP patients have a common point of view about the reason of their social exclusion. This common reason is lack of the public awareness and knowledge about RP disease.

### 5.7.Stigma, Discrimination and Exclusion:

In this part interviewees discussed about discriminations and mistreatments that they were experiencing in their social context.

**Iran**:

One of the Iranian respondents said that she feels she does not belong to the Iranian society:

*"Disabled people become isolated here. There is a negative approach among the public, so the disabled limit their communications to their families because of cultural poverty (lack of knowledge) in public about RP. In our society emotions and humanity is important because of dominant religious beliefs in the social context and they have pity and sympathy for us"***.**

These statements indicate that RP patients deal with stigmatized behaviors as a result of socialization of stigmatized norms against RP people in Iranian context. They are confronted with such treatments in family relationships as well as their interaction with public people. According to the concept of govermentality, hidden powers socialize people in family and other places of interaction to obey and act in limited inflexible norms about visually impaired people. This behavior which is the fruit of prejudices is part of social oppression and social exclusion which are imposed by social interaction to RP patients. (Lukes, 2005)

One of the Iranian respondents mentioned:

*"Visually impaired people are isolated and excluded from the society; therefore they cannot communicate with other people after living and educating in separated schools for visually impaired people, according to norms. They feel segregated and undeveloped in communication with other people outside home, when they graduate. They feel that they should adapt themselves to new social context, which takes a long time. Moreover they socialized in another normative context by living and educating in special schools for visually impaired students".*

This respondent underlined that he was excluded by segregated education. Indeed he has not even low chance to communicate with other people in the society. I have noticed that RP patients do not have equal access to education, therefore educational institutions exclude them from integration with the society regarding to social oppression theory. (Barnes, Oliver & Barton, 2002)

One of the Swedish respondents stated that:

*"I think we are facing difficulties, but this is due to the normative aspects in our society. I think I can be better included in the society but this also requires more effort, from my side. I cannot blame the visual impairment for all my problems.*

This respondent dealt with exclusion as a result of norms and values about visual impairment. At the same time he underlined that he can affect this exclusion by his role in society. (Mead, 1934)

One of the respondents mentioned:

*"I have this feeling that I am outside of the society. I believe that there are limitations to inclusion, structural limitations and attitudinal limitations, but I am very happy to live in Sweden, because we have good opportunities. I believe that I can find good jobs if I continue my education and be qualified in higher levels. Then it is more possible that I can get jobs equal to healthy people".*

I noticed that this respondent has experienced exclusion from society mostly in entering labor market through dealing with stigmatized norms about visually impaired people who are not able to work as equal as fully sighted persons. His reaction and coping to decrease this exclusion is to put more effort in education in comparison to fully sighted people. He believes that attitudinal norms about being visually impaired can exclude RP people in getting job. (Goffman, 1963)

Another respondent stated:

*"It depends on what kind of society you live in. I feel that I am included in communities and the society, but because of RP I cannot do exactly everything that I perhaps would wish to do. In that respect there is some exclusion, that I do not sense them as exclusion. I'm not happy because I would like to do many things but one has to accept the situation. You cannot change that situation; you cannot imagine that you can drive a car, so you just have to accept those kinds of limitations".*

The above mentioned respondent dealt with exclusion due to her limitations to do activities e.g. driving, through living with RP, an activity that she used to do before losing her sight. Her reaction to this exclusion is accepting these limitations with the belief that there is no solution for them.( Eckenrode,1991)

**Comparison:**

According to the findings, I found out that both Iranian and Swedish respondents do not feel fully included in their societies, in fact they are dealing with social exclusion and discrimination for different reasons such as structural and attitudinal limitations, relevant to normative aspects and social position of individuals. Iranian respondents believe that there is negative approach and lack of knowledge regarding visual impairment among public. They also mentioned that some of their social isolation limiting their communication and interaction with the society came from emotional norms instead logical norms in their society. Iranian respondents are dealing with a lot of emotional reactions from strangers and even family members which make them avoid to have interaction with others and limit their relationship to family members. Based on the findings, respondents in both countries, deal with exclusion and discrimination in both levels of family and friends and working relationship.

**Common issue**:

Although both countries have ratified social policies for disabled people but in practice RP patients still deal with stigmatized social identity and social exclusion as the consequences of administrators' actions through internalizing inflexible norms about acceptable characteristics of individuals with ideal health factors as a common sense, in both social contexts regarding concept of govermentality. According to these norms and socialization processes, practiced by different administrators like parents and teachers, individuals have a framework to communicate and interact with others in society. In brief, it can be concluded that macro level education has a weak function in practicing and enforcement of the norms regarding disability policies in both social contexts.(Lukes, 2005)

### 5.8.Structural Obstacles: (Accessibility of public transport, public buildings and standardized environment)

In this part, I have described about the access of RP patients to public transport, public buildings and streets in both countries. Regarding the Swedish respondent's statements, all buses and trams are equipped with speakers for announcing the stations, but sometimes drivers do not turn these facilities on, so RP patients face problems in recognizing the stops and they lose their way".

One Swedish woman mentioned:

*"Yes, there are announcements about stops for the blind people, but the equipment does not work all the time. I think one solution is training of drivers, because in buses and trams there are facilitations but the drivers do not activate them all the time".*

**Comparison:**

Iranian RP patients deal with lots of non-standard structural problems in City of Tehran. For instance, there are lots of curbs and iron bars in streets which injure RP patients. One of the Iranian respondents mentioned that "Subway is the safest public transport for me because I have personal assistant in metro. Access to personal assistant in subway is obligatory after dying of a blind person in Tehran subway. Regarding buses, few of them are equipped with speakers. According to respondent's statements in Iran, most of the public places are non-standard and unsafe for visually impaired people and the only safe public transport for them is subway. They mentioned that access to personal assistance in subway is easy for them because since 2 years ago after dying of a visually impaired person due to an accident in Tehran metro, all the blind people can get assistance. In comparison, Swedish respondents face fewer obstacles in the city context. Although most of buses and trains are equipped with speakers, sometimes drivers do not turn on the speakers and Swedish RP patients have difficulties to stamp their tickets. (Barnes, Oliver & Barton, 2002)

**Analysis:**

Non-standard network increases the RPs segregation. So they have a lower chance to have entertainment and experiencing new activities. They will be more dependent to family environment. So they cannot learn and apply social skills by this immobility and segregation. On the other hand, social systems and authorities do not provide any standardized equipment. Non-standard and unsafe environment in opposition to legislation indicated that there is failure and mismanagement in enforcement of legislation. Indeed Iranian government causes social oppression and exclusion for RP patients through neglecting their needs. Swedish government facilitates the environment for RP people to have their independency by providing equipped and safe environment and accessible public transport and buildings. In other words, Swedish government is trying to decrease some parts of RP patient's social oppression by providing accessibility. (Barnes, Oliver & Barton; 2002)

## 5.9,Social Services:

In this part, RP patients have been described their access to social services in both countries. Following there is a comparison between two countries.

Some Swedish respondents mentioned that they have access to free white cane and glasses. They can use taxi with very cheap price. People with disability can apply for taxis with doctor prescription through local authority. They have an online access to audio books and music in some libraries in the big cities. (Barnes, Oliver & Barton, 2002)

Here, I discuss the RP patient's access to libraries and books through updated services in Sweden:

TPB is the national Centre for the inter-library lending of audio books and maintains a stock of 63000 DAISY (Digital Accessible Information System) talking book titles and 28000 analogue talking booktitles ; acquiring approximately 3000 books annually in Sweden. TPB´s stock contains books in fifty different languages. Furthermore, university level students with a print disability can borrow course literature in alternative formats.TPB publishes 300 titles in braille annually and stocks almost 13000 titles for lending purposes. Many titles can also be purchased. Most braille borrowers have direct contact with TPB and many titles are provided on request. Visually impaired people have also access to picture books interleaved with braille and tactile picture books provided by TPB. A consumer service for the deaf-blind and blind transcribes personal papers and correspondence, magazine articles, prescriptions, manuals etc. Visually impaired disabled persons can borrow talking books from municipal and school libraries. (http://www.tpb.se/english/)

Iranian respondents stated that National library has a unit for blind people in this library and in one center they have access to audio books, but they have a limitation where they can just borrow two books each month with an expensive price. In compensation, in recent years some private centers provide the same services with a very cheap price and no limitations for borrowing audio books, for blind people but due to transport difficulties for the visually impaired people they can hardly access to National library which is located on a big site in Tehran highways.

According to the Iranian respondents, airplane ticket is half price for visually impaired people, they have access to assistance in subway, and they have a supplementary and health insurance. They also underlined that there is a lack of white cane and audio watch. Some Iranian respondents stated that there are a few sport complexes placed in far distances for visually impaired people in far distances and it is too risky and expensive for them to reach to these clubs, so they prefer to do indoor sport activities. They also underlined that "There is a lack of white cane and audio watch for us". They also mentioned that the Iranian made canes are low quality and easily broken compared to foreign produced canes. He also highlighted that, they do not have access to Daisy system which is very useful for visually impaired people but service providers do not equip libraries by this system and they are still using MP3 system. (Barnes, Oliver & Barton, 2002)

**Comparison**:
I found out that Iranian respondents deal with more problems in receiving social services, compared to Swedish respondents. They do not have free access to white cane and audio watch; they have limitations in access to audio and braille book. They do not have online access. They do not have access to buses equipped by speakers and specific taxis for disabled people. This indicated that although there are suitable policies on paper (legislation for disabled people) but there is no enforcement in practice. On the other hand, Swedish respondents have more access to IT and readable materials. Inaccessibility to resources, influences different aspects of RP people lives, especially in Iran. Iranian respondents deal with more segregation since they do not have easy access to books in their free time. They will be more dependent on their family members and environment since they have unsecure outdoor environment to have access to libraries and sport clubs. Iranian respondents have low chances to increase their individual skills and knowledge time in comparison with Swedish respondents who have online access to library and equipped public transport. Inaccessibility to secure public transport also influences their participation in different communities such as RP community. Furthermore, Swedish respondents have more chance to integrate with society through their access to libraries, thus they can have a rich individual life. In other words, Swedish welfare state provides opportunities for RP patients to decrease some parts of social oppression and exclusion of this group in practice. (Barnes, Oliver & Barton, 2002)

### 5.10.Public Awareness:

In this part respondents were asked to explain their idea about public awareness and public reactions to RPs. Public awareness is defined as the knowledge and reactions of ordinary people in public places in dealing with RP patients.
One of the Swedish respondents highlighted that:
*"We have the society of infrastructures and social infrastructures and gets in when someone has problem, which means your personal responsibility for other people is reduced, so that culture allows someone to have pain because it is a way to handle it."*

One of the Swedish respondents outlined that:
*"It is up to us. I include every one and it is up to every single person, so it is the matters of taking individual responsibility. Responsibilities lay to everyone."*

**The author's reflections:**
Swedish respondents believe that strong and broad welfare service provision

decreased individual responsibility of family members in helping each other. They believe that Swedish welfare state produce a culture of leaving people with their pain with the assumption of gaining help from welfare state. Using white cane in public places has a strong relationship with public knowledge and public reactions to RP patients. (Lukes, 2005)

Two of Iranian respondents mentioned:

*"People do not have knowledge about visual impairment and even blindness, there is a cultural poverty and poor knowledge about visually impaired people among public".*

According to these statements, Iranian RP respondents are dealing with low awareness of the people about RP disease and there are stigmatized norms about being visually impaired in Iranian social context. Thus RP people are suffering from prejudices and lack of knowledge which are part of social oppression among disabled people. These norms and lack of knowledge makes uncomfortable situation for the disabled to get help and social support, and isolates them from attending and interacting in public places. Low public awareness might lead RP patients to deal with discrimination in entering labor market and to improve in job environment. (Goffman, 1963)

Two professional respondents who work with RP patients in an eye clinic in Gothenburg mentioned their views about the process of individual acceptance and integration of RP patients according to RP characteristics and Swedish social norms and reactions about being visually impaired and fully sighted*:*

*"It is very often that they do not want to use white cane and they do not want to show it. For RP patient it is very hard to decide about using white cane. They think it is a shame to be blind or visually impaired. Some RP people said that they prefer to hide their problem from their bosses and managers, even their colleagues because there would then be the risk of losing their jobs. They also do not tend to show their visual impairment because they may lose their self-confidence. It takes a long time for RP patients to accept their visual impairment because although they lose their environmental vision but they have a pretty good central vision, so it is very hard for them to accept that they are going to become thoroughly blind. Although RP patients have a possibility to read and see small things but they are unable to work. Although we have great legislations, they can easily get fired indirectly".*

Swedish respondents have different beliefs about reasons of low awareness among people in Swedish context. Some believe that strong social welfare system reduced individual responsibility of the public to help others. Another respondent believed that RP is very complicated in nature, due to many factors, so it is hard for people to understand it and communicate with RP patients. Other respondents believed that increasing public awareness about RP disease is a task and responsibility of RP patients though talking and communicating with people with the aim of increasing their knowledge about RP. (Lukes, 2005)

**Comparison:**
Respondents from both countries have dealt with limited norms about using white cane through their interactions to ordinary people. Ordinary people could not trust to help RPs considering their social norms about being visually impaired. Furthermore, they have coped with unemployment which was a consequence of poor knowledge and stigmatized norms of ordinary people about RP disease.

## 5.11.Some interesting findings:

-RP patients' individual acceptance can be affected by their families' reactions to them, while living with RP. As regarded this issue, some participants have problem solving reaction against logical behavior of their family members .On the other hand, they have emotional coping when faced by mistreatments and misunderstandings. Considering these two groups of RP patients, they have common problem solving coping reactions such as joining communities, changing their individual attitudes through focusing their abilities instead inabilities caused by visual loss.

-RP patients exclude each other through being socialized by stigmatized norms against visually impaired people in the society. In practice, they avoid to choose RP patients as partner or as close friends. This indicates that the how stigmatized norms against visually impaired people, have affected them to exclude each other.

# Chapter 6:

# Discussion and Conclusion:

In this part, research questions are answered according to research aims, by utilizing the theories as well as the author's viewpoints.

### 1. What are RP patients' challenges according to three levels of micro, mezzo and macro?

In this part, RP patients explained about their families and friend's reaction while they lived through RP. Furthermore, they discussed about their social support gained from, or influenced through losing vision and living with RP. What are their challenges and obstacles considering employment, access to public transport and public places, social services, social policies and interpersonal communication?

## Challenges in Micro level:

This section deals with mistreatments and exclusions of RP patients in different levels of their life. The author understood that these behaviors affected their individual and social life, to a large extent. Stigma theory and its concepts was in fact a good facilitator to explain their situation. Considering definitions of personal and social identity for stigma management, both Swedish and Iranian respondents were found to be influenced by stigmatized social identity in re-defining their personal identity during their interaction with society in different levels; mezzo and macro. In fact, their personal identity was affected by their social identity during stigmatization process. Their personal and social identities affected their individual acceptance within the society and their access to social network. RP community influenced their individual acceptance through coping with RP. Iranian RP respondents were dependent on their family support to join RP community while Swedish respondents did not depend on their family and friends to join and participate in RP community. Lack of accessibility to public transport in a safe mode and non-access to information technology have been the two important factors which affected participation of Iranian respondents to interact into outdoor activities, e.g. participation in RP and similar communities. Stigmatized identity of RP patients is a consequence of some inflexible socialized norms. For instance, RP patients were uncomfortable to ask for help as social support. Both respondents from two countries experienced difficulties in their close relationships like finding a partner. Moreover, unemployment is another individual challenge for both Swedish and Iranian respondents. Unemployment is mostly a consequence of specific norms about entering the labor market by the visually impaired people. Respondents mostly emphasized that fully sighted people were in priority for employment. Considering stigma theory, respondents' social identity was stigmatized by norms about:

Accepting the person in the society in different aspects e.g. friendships, entering labor market, have partner, access to public transport and public places.

Research findings indicate that using white cane has a great impact on access of RP people to social support in public places. This illustrates the fact that how ordinary people are socialized about white cane application. RP patients should build a trust by using white cane in order to be able to get help in public places or from service providers. Finally, RP patients live through unstable vision which affects their daily activities. Dealing with this unstable process might make difficulties for them to find a balance between their ego identity and social identity.

## Challenges in Mezzo Level:

It seems that participation in RP community is the most useful process in RP patients' life. Participation can increase their individual and family acceptance. RP patients can increase their individual and social skills and abilities through their participation in the society. The author believes that, community and participation has a strong relationship with RP patients' coping process and getting social support. Furthermore, RP community can increase the integration of RP patients to the society through social networks.

There are two different reactions among Iranian families of RP people. Some of the family members supported RP patients emotionally, but some did not accept their RP children as equal as their healthy and fully sighted children.

Regarding to Mezzo level, RP patients have argued about their participation in RP or similar communities which provide activities and services for RP patients and visually impaired people. Moreover, the author noticed that RP patients had different ways of coping about their participation in RP community. Inactive respondents had an emotional coping and active respondents had problem solving focused coping through their idea about participation in RP association. Active respondents have two types of coping during their participation in RP community. They compare themselves with other RP members in two ways. They are inspired about successful people and appreciate their facilities and abilities compared to other RP members with lower education and lower vision.

Besides physical limitations as consequence of low vision, RP patients in both countries deal with similar individual barriers such as unemployment and high probability of losing their job, difficulties in finding partners or getting married and they usually avoid to join social gatherings. Their physical limitations such as inability to do their activities independently they become slow and everything takes longer time.

Based on research findings, there is a communication gap between RP visually impaired people, and policy makers. RP patients are voiceless in transferring their needs and shortages. Association is the only social place where social identity of RP patients is not stigmatized and they can gain social support and reinforce their social and ego identity by interacting with other members, there. Community is an effective facilitator in decreasing social segregation and isolation of RP patients. RP community can increase the public awareness about social and political system allocated for the visually impaired people. Democratic bases of Swedish political system provide an open society for civil interactions such as free actions of communities. In Iran, in spite of the Iranian Constitutional Law that enables every citizen to connect to the parliament members and propound their problems in order to improve the situation, in practice there are many barriers to implement the law and perform the written policies. Community is a good resource for RP patients to increase their individual and social acceptance. Their participation in RP and similar communities which are active for visual impaired people, have some advantages. These activities provide opportunity to increase their social network, exchanging their experiences about coping with RP, sharing their common experiences and decrease social segregation. Communities are dependent on resources and free environment for free act, to improve the RPs social life through effective communication with policy makers.

## Challenges in Macro level:

In this part, RP patients have argued about their access to public transport and social services at Macro level:

Violation of visual impaired peoples' rights includes inaccessible public transport, limited access to libraries and audio books, limited number of sport clubs, and finally unemployment of the visually impaired people. These indicate the government's mismanagement and malfunction towards enforcement of social policies. Mismanagement in distributing resources and budgets has shown an insufficient and inefficient action of health administration in Iran. On the other hand, mismanagement of social and human capital utilization e.g. employment of professionals within the RP community is also another significant factor for unsuccessful policies of the government, in Iran.

Macro level includes access of RP patients to public transport, social services, public places, role of policy makers and the issue of public awareness. Public awareness has been discussed as a factor affecting RP patients' life through gaining social support in public places. These factors have been discussed as separated sub titles in this level. Social oppression theory covers all parts of the macro level life of RP patients. RP patients suffer from prejudices and norms against them, their stigmatized identity, low public awareness, inaccessible public transportation and lack of social services.

Social oppression theory also covers all parts of macro level life of RP patients. RP patients face prejudices and stigmatized identity, low public awareness, inaccessible public transport, inaccessible public buildings, and lack of social services (Barnes, Oliver & Barton, 2002).

Findings indicated that using white cane influenced the access of RP people to social support in public places. It shows that how people are socialized about use of white cane and visual impairment. The author believes that normative views about white cane application are inflexible. According to Foucault, there is a tendency in socializing and educating people by mass media and educational system. Therefore base on Foucault idea, there is a relationship between powers. Some powers are more dominant in this relationship and they have more influence, because they have more resources and wider access to those resources. Authorities do influence (Lukes, 2005).

**Comparison between Sweden and Iran Regarding the Macro Level:**

Here is a comparison between both Iranian and Swedish RP patients at Macro level, based on social oppression theory. Swedish government has reduced some parts of the social oppression of the disabled people by developing and enforcing policies through transportation act, IT strategy and the justice system that I mentioned in the introduction section. According to these policies in Sweden, the RPs have access to public transport as equal as others, also access to information (digital inclusion), access to modified housing and group housing, serviced apartment and access to funding for job hunting, are other benefits considered for the RP patients in Sweden. People with disabilities can also receive various types of financial assistance from the Swedish Social Insurance Agency. Since the Service providers are not quite familiar with RP and its characteristics, RP patients deal with difficulties to gain financial assistance. According to the research findings, lack of sufficient awareness of employers in labor market about the rights and problems of RP people still leads them to give the priority to fully sighted people. Furthermore, they deal with discomforts in getting social support and social interaction, being exposed to exclusion and isolation in their family relationships, friend relationships and public places.

On the other hand, Iranian respondents deal with all aspects of social oppression mentioned in social model of disability. Besides access of disabled people to half price public transport, there are no actions and enforcement in providing accessible public transport and modified housing for disabled people. Although there are policies for provision of sport and cultural activities for disabled people in Iran, but RP respondents deal with lack of sport facilities and cultural activities. Furthermore, Iranian RP patients cannot use these facilities in an environment of unsecure public places and inaccessible public transport. Iranian disability policy might decrease the social oppression of disabled people specifically RP patients by providing free education , access to half price public transport, access to standardized public places, rehabilitation activities, health care insurance, complementary health care insurance, exemption from military, allocation of 3 % of civil employment to disabled people, allocation of 2 hours of weekly media programs to increase public awareness about disabled people, allocation of 10 % of cheap price houses to disabled people, however, there are barriers in enforcement of all these policies in practice. For instance, RP patients have no access to standardized and safe public places and public transport. Moreover, Iranian disability policies have some inefficiencies and problems like no access to modified housing, standardized public transport, information technology and resources, and limited access to audio books.

According to findings, performance of social welfare state as a factor of macro level has influenced Swedish and Iranian social norms differently. Service provision of Swedish social welfare state provides opportunities for individuals to be more independent. But on the other hand relying on these regulations has reduced the sense of the people's responsibility and sympathy towards each other.

In contrast, the Iranian social welfare state made the RP people more dependent to their families, due to the shortages of service provision, unsecure public environment and limited environment to do civil activities, for enhancement and improvement of their rights. Hence, Swedish RP patients have more access to social and environmental resources in order to deal with difficulties through living with RP. In conclusion, authorities, policy makers and service providers have the main role in providing access to different social services and policy making against stigmatized normative approach.

Respondents from both Iran and Sweden deal with low public awareness, lack of knowledge about RP disease, and there are high levels of stigmatized norms among public people and professionals about the visually impaired. It seems that authorities and policy makers have a strong role in socializing norms among citizens through macro education at schools and mass media, at university, public places, work places and professional community, both in ratification of policies as well as in practice. Authorities could have an effective role to increase public awareness and improving norms against visually impaired people due to their access to resources in macro level. They could be the effective facilitator between RP patients, policy makers, service providers and public people. I believe that there is a communication gap between RP patients, academics, service providers and policy makers in both countries. Considering the importance of public awareness in reducing the social oppression according to prejudiced and stigmatized norms about visual impairment specifically RP patients, authorities should allocate enough resources and budgets to increase public awareness about RP patients and socializing norms against stigmatization of visually impaired people in macro education systems e.g. schools, universities and mass medias (Barnes, Oliver & Barton,2002).

### 2. How three levels of RP patients' life are interconnected and influence each other?

In this part, relationship and influence of three levels of Micro, Mezzo and Macro level in life conditions of RP patients is discussed. The author finds that individual barriers and personal coping are highly influenced by function of mezzo and macro level of RP patients. For instance, in coping process, their reactions through applying problem solving coping is a response to change and resist against common stigmatized behaviors and norms in the social context.

### An example of Interconnection between Micro and Macro level:

Lack of public awareness as one of the main factors, with vital role in Macro level, might highly affect social and individual acceptance of RP patients in both countries. Lack of public awareness leads to exclusion of RP patients from social support, through family and friend relationships. It also excludes them to get social services and public transport from service providers in macro level. According to research findings, misunderstanding and lack of sufficient knowledge of some people about disabled people, caused to some situation, for instance the bus and train drivers do not turn on the speakers to let the patients know the stops. Moreover, some service providers in financial agencies do not represent financial and home assistance to RP patients according to their poor knowledge about RP disease. Low public awareness stigmatizes RP patients' social identity considering stigmatized norms about being visually impaired. One part of the public awareness is highly influenced by socialized norms and values about being fully sighted and being visually impaired. It might be interpreted that authorities, policy makers and service providers internalize these norms according to their tendencies by internalizing specific norms through mass media and macro education. Consequently, these norms have been socialized and practiced in society in long term at home and among peer groups according to governmentality concept of Foucault. (Lukes, 2005)

Moreover, low public awareness influences the RP patients' life in getting social support in public places. Public awareness of their colleagues and bosses causes discriminatory behavior and reactions and exclusion in job environment. Low public awareness has lead them to deal with exclusion and misunderstanding from their family members and friends, and low public awareness of service providers about RP can exclude RP patients in getting social services fairly. So public awareness, as an important factor of macro level, has strong effects at Micro level.

### Another example of relation between micro and macro level:

RP patient's unemployment is a consequence of stigmatized norms, lack of knowledge and low awareness of the public which indicates the relationship and influence of macro level factors to micro level. Furthermore, avoiding participation in friends' gathering is the result of being excluded and stigmatized, a situation that affect their social network and social interaction as a part of Micro level.

**Relation between Mezzo and Macro level:**

RP patients' participation in formal and informal communities is an example of utilizing their collective power to affect and influence the efficient factors in macro level such as policy makers and authorities in order to improve their rights and enforce their needs. But, utilizing this collective ability through communities needs access to social and economic resources and a free environment. Communities would be good facilitators in decreasing the gap between service users and policy makers as well as service providers. (Adams, Dominelli&Payne, 2009)

**Relation between Micro level, Mezzo level and Macro level:**

Iranian RP respondents are dependent on their family support to join RP community but the Swedish respondents were found not to be dependent to their families to join the community, according to two different social contexts. This statement indicates that, respondent's participation in communities might be affected by families' decision and role, as a result of inaccessibility of patients to social services. Actually, access of respondents to social services can provide their independency regarding their families, and increase their access to social support and social integration.

### 3. How do RP patients cope with their disease and social limitations personally?

How do the RPs participate in improving the life condition of disabled people?

Accessible Social opportunities can help respondents to apply problem solving reaction through their coping with social limitations. RP respondents from both countries got perceptional support from their participation in RP communities. For instance, they changed their perceptions about dealing with RP by getting informational support. They got informational support through exchanging their experiences and knowledge about RP disease in RP communities.

The author finds out that respondents have two kinds of coping through their participation in RP community. They compare themselves with other RP members in two ways. They are inspired about successful people and they appreciate their facilities and abilities compared to RP members with lower education level and lower vision. Through this coping, they reinforce their abilities instead of focusing on inabilities caused by social limitations.

Respondents have different reactions to participate in improving the situation of disabled people through their access to social and environmental resources. Considering social inequalities and obstacles, Iranian respondents have mostly chosen individual action to improve the situation of disabled people in Iranian context. In contrast, Swedish respondents have chosen collective participation in order to improve the RP people's life condition regarding their access to social opportunities, resources and free environment.

## Conclusions:

Here, discussions about some conclusions obtained through the study are represented.

-Using white cane influences the access of RP people to social support in public places. RP patients should build a trust for ordinary people in public places in order to be able to get help from the people in both countries.

-Iranian women deal with double social oppression as RP patients in entering labor market, integrating in Iranian context, and lower chance to get married. In some families the RPs have been experiencing discriminatory behaviors through family relationships such as being hidden in family gatherings as a consequence of being an unaccepted and shameful member of the family. Normative approach of Iranian context about being visually impaired woman produce individual and social stigmatization and segregation for these women. Gender inequality produces more social oppression for them. This issue indicates the relation between public awareness as a part of Macro level and being deprived from social network and social rights such as employment and marriage as an individual. In contrast, Swedish women respondents did not deal with these gender inequalities in Swedish context.

-In both countries there is a need to raise public awareness of RP patient's situation and implement social policy changes for this group.

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**Internet Resources:**

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  http://www.rpinternational.org/about-rpi/helen-harris.html

- http://www.sweden.se/eng/Home/Society/Accessibility/Facts/Swedish- dility-policy/#idx_6

- http://www.retina-international.org/eye-conditions/retinal-degenerative-conditions/rp/

- http://www.srf.nu/leva-som-synskadad/rattigheter/Hemtjanst/

- http://www.kvinnonet.org/essays/FA0124.html

- http://www.independentliving.org/standardrules/UN_Answers/UN.pdf

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- http://farhang-ashora-001.blogfa.com/post-71.aspx

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- http://www.djurforsok.info/nyheterreportage/nyheter/lovanderesultatforna thinneforskning.4.20a9b749116aab4d13680001

- http://www.tpb.se/english/