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Chronic Illness

including a portrait of the organization „ChronischKrank“

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1 Introduction

Since 1900 in the EU there was a displacement of the disease spectrum given from acute to life-long persistent chronic diseases. That was the reason for us to look a little bit closer at chronic illness and the social consequences for concerned people. At the example of the organisation „ChronischKrank“ we get a little bit more insight of the problems chronically ill people have to deal with.

2 Definitions

2.1 Health

The WHO (world health organisation) defined health 1946 as: „a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.“

Hurrelmann's, a health - sociologist, definition from 2006 is:

Health refers to the condition of the well-being of a person which is given if that person is physically, psychologically and socially in accordance with the relevant internal and external conditions. Health is to understand as a pleasant and not self-evident equilibrium stage of risk factors and protective factors that must be made at any time of biography. If there's a balance, then the joy of life and sense can be gained, a productive development of the skills and performance potential is possible and the willingness to integrate themselves socially and to get involved increases.

2.2 Illness

Hurrelmann's definition of illness:

Disease is the stage of the imbalance of risk and protective factors, which occurs when a person's internal (physical and mental) and external (social and physical) requirements aren't fulfilled. Disease is one stage in which a person conveys an adverse effect on his wellbeing and his zest for life.

Pschyrembels definition from 1994:

Disease is defined as "disruption of life processes in organs or in the whole organism, with the result of perceived or objectively verifiable physical, mental or psychological changes"

2.2.1. Acute Illness

Acute diseases are infectious diseases caused by microbial pathogen (bacteria, virus). They are only temporarily, caused by pathogens and terminated after extinction of the pathogen.

2.2.2. Chronic Illness

Chronic diseases: by prolonged congestion of the physical, psychological and social adjustment forces initiated, it comes to heart-circulatory diseases, cancer, metabolic diseases and mental diseases. (Hurrelmann 2006)

3 „ChronischKrank“

The organisation „ChronischKrank“ was founded to support chronically ill people.

3.1 Offers

It offers support for handling government Affairs and financial support.

You can get psychosocial and medical mediation and find exchange of experiences with other affected people. Also you get advices in food & health coaching, case management and disease management.

3.2 Goals

Goals of the organisation are:

- Representation of the chronically ill and their families
- Chronically ill people to make the access to funding and support as easy and transparent as possible
- One-stop shop for advice, escorts, agencies, mediation and support

- To provide for social, medical, legal affairs and psychological assistance and mediation.
- Lead chronically ill people together to share experiences to ensure a better disease management.
- Scientific research in chronic disease management and disease management or case work and to publish it.
- To install “Disease management and case management” successfully in the Austrian health system.

4 Kinds of chronic illness

In my part I want to connect health sociology in generally with specific situation of people with chronic illness. We will have a look at the widespread kinds of illness, so that we can see, which effects are in social life of the aggrieved party.

At first, I want to make a distinction in chronic illness, that everybody can see, and whom, that are not obviously. This is, I guess the most deciding sign, how circumstances and society will react. Also I know that the topics are much more complexly, I want to treat these two stereotypes, because of limited time.

Both groups are endangered to become part of social outsider group and experience social exclusion. Afterwards everybody can make her/his own opinion, which one is more or less discriminative and how specifically problems brand their life's.

So let us start with the ones, who have apparently illness or are bodily handicapped in any way. Members of society are estimated people with demonstrative attributes, because they are outside the norm. And not depending, whether evaluation is positive or negative, this behaviour leads to developing clichés and prejudices. We can summarize this phenomenon in the word „stigmatization“.

5 Stigmatization and social exclusion

Primarily stigmatization was conducted to punish. If somebody for example perpetrate thievery, the hand was chopped off. The goal was public ostracism and is sure, that these people will be social outsiders forever.

In special case of chronically illness, stigmatization and discrimination often sway the behaviour in looking for aid and support in any way. This means, that there can be a negative effects on prediction, and impair life quality fort these people.

Definition of „ Social Outsider Groups“ in sociological context:

Friedrich Fürstenberg, which was working and teaching also at the JKU constrained, that an social outsider group is the fusion of people, who have less recognition in generally binding social cultural values and norms. They are signed, because they cannot realize their social life as other members in society.

„Zusammenschluss von Personen, die durch ein niedriges Niveau der Anerkennung allgemein verbindlicher soziokultureller Werte und Normen und der Teilhabe an ihren Verwirklichungen sowie am Sozialleben überhaupt gekennzeichnet sind.“

(www.socialinfo.ch/cgi-bin/dicopossode/show.cfm?id=583 download 25.4.2010)

Finally this is a vicious circle: Outsider groups will be stigmatized, and stigmatization leads to exclusion and developing of outsider groups.

6 Situation of chronic ill people

Because of any „deficits“ (in education, finical income, language, religion...) people are not included in core society completely, and are seen as a group, which is worthily to support. Chronic ill people are one of scores of marginal social groups.

But very often, illness cannot be seen and presents extraordinary charges. Before Jürgen will introduce special cases of effects and resulting needs of people, who are chronic ill, I will give some examples of massive drawbacks:

- | | |
|------------------------|---|
| 1. financial situation | charge for rehabilitation and drugs, loosing job... |
| 2. judicial situation | right to a pension... |
| 3. labour market | re-entry and re-training... |
| 4. social life | Ronni will talk about afterward... |

7 „Statistik Austria – Health – Report 2006/07”

The upward tendency of the life expectancy has also increased the concerning chronic illnesses. The lifestyle is also jointly responsible. Parts of the people don't eat healthy food, they have too less movement and often they are smoking. These are important reasons, why people are ill. At this time, so the „Statistik Austria – Health – Report 2006/07 ”, 60 per cent of the male population has at least one chronic disease. On the other hand are 69 per cent of the female population has at least one chronic disease. The most important chronic illnesses are high blood pressure, damage at the spine, arthritis and the chronic illnesses of kidney, heart, liver and lung.

8 “Case Management”

A strong emphasis of the organisation ChronischKrank is to support people they have kidney inflammation and the dialysis. People who must have dialysis have no kidney function or not enough function.

These are results of diabetes or inherited kidney inflammation.

After all, these people must go to the dialysis 3 days of the week and per day for about 6 hours.

In this case it is very important to support this people with case management to get a better disease management.

Intensive “**Case management**” services are a key part of the continuum of mental health services and supports for people with serious mental illness. The direct involvement of the consumer and the development of a caring, supportive relationship between the case manager and the consumer are integral components of the intensive case management process. Case managers work to build a trusting and productive relationship with the consumer and to provide the support and resources that the consumer needs to achieve goals, stabilize his/her life and improve his/her quality of life.

- Outreach and Consumer Identification
- Assessment and Planning

- Direct Service Provision/Intervention
- Monitoring, Evaluation and Follow-up
- Information, Liaison, Advocacy, Consultation and Collaboration

(http://www.health.gov.on.ca/english/public/pub/ministry_reports/mentalhealth/intens_cm.pdf download 8.april 2010)

9 The „Eurotransplant International Foundation”

A very important precaution is a healthy life style, as well as much movement and no smoking. But in contrast many people have an inherited or immune deficiency. These illnesses are also a result of the high life expectancy.

One ray of hope have the sick people and this is the organisation „Eurotransplant”. The „Eurotransplant International Foundation” is responsible for the mediation and allocation of organ donation procedures in Austria, Belgium, Germany, Luxemburg, the Netherlands, Slovenia and Croatia.

In this international collaborative framework, the participants include all transplant hospitals, tissue-typing laboratories and hospitals where organ donations take place. The „Eurotransplant” region numbers well over 122 million. In Austria the hospitals had transplanted 813 kidneys, 45 hearts, 104 livers and 92 lungs, from January 2008th to March 2008th.

(download 8.april 2010 <http://www.statistik.at/>)

In general, this people need a lot of support like social, mental, financial and medical help and this is the reason why people need a “disease management”.

10 “Disease Management”

“**Disease Management**” is a system of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant.

Disease management:

- Supports the physician or practitioner/patient relationship and plan of care.

- Emphasizes prevention of exacerbations and complications utilizing evidence-based practice guidelines and patient empowerment strategies.
- Evaluates clinical, humanistic, and economic outcomes on an ongoing basis with the goal of improving overall health.

(download 8.april 2010 http://www.chronischkrank.at/disease_management.html)

11 Chronic Illness in Social life

Chronic illness is a heavy burden for the concerned persons, as well as for their family members and friends. The next of kin cares about the situation of the sick person and is involved in the disease management. The psychological strain is exceeding high. Usually the relatives have eight hours per day job and after work they have to take care of the patient. During the day they are filled with sorrows and think about their duties and responsibilities. Furthermore, they need to be strong for the people they love and that need them; it is their moral obligation to support the patient however they can. Chronic illness is a force in sociological, financial and mental life.

In this crucial situation, the diseased people and their relatives would search for help. They have to knock on many doors, until they get the right answers and help. It is not easy to find the competent offices and agencies in the particular case. There is no institution of public needs, which serves as a central organization for all belongings.

Chronic illness affects us all. Heart attacks, apoplexies, cancer and burn out syndrome: those are the most popular diseases in our time. A statistic says that more than a third of the population between the age of 15 and 30 years is hit by chronic pain, and beneath the people, aged over 60 years the percentage is even more than 66%. If we look at the demographic employment, we can see that the situation will not get better in the next future.

11.1. Employment and Solutions in Civil Society and Politics

The goal of the organization “ChronischKrank” is, to be that center for all sick persons and their next of kin. We want to give them the information, where they can find the solution of their problems. Our knowledge and our experience can help to make ways shorter, faster and easier.

We know sick persons do not need our pity, they need help and solutions.

As we look at the change of the family structures we see that the care, raise and education of the children are often the duty of single parents. In Austria there are 114.400 single parents with children under 15 years (Statistik Austria). 90% of them are women. If the only attachment person falls in an illness, the child or children would get an extraordinary pressure. On the other hand we see how hard it is for a single person to handle the job and the disease management. The salary in part time work is mostly too low and foreign care is very expensive. It is a depressive and desperate circle.

In my opinion it is necessary to found regional self aid groups to solve the education and care problems. Furthermore, the politics have to focus on the social aspects of the concerned families for more financial and mental support. Especially for single parent mothers there has to be a special fund. It seems that the social care is more and more public affair and work of NGOs and NPOs and no more in the interest of the government.

Diseases and chronic illnesses are a fact in our society; we have to have the laws, the financial resources and the needed aid. We all have a collective responsibility that we cannot shift; it is a challenge to all of us to find adequate solutions for the complex problems.