The wings of a butterfly:

Reproductive life and self image of Dutch women with epilepsy

Papreen Nahar

THESIS

AMSTERDAM MASTER'S IN MEDICAL ANTHROPOLOGY
UNIVERSITY OF AMSTERDAM
THE NETHERLANDS
1998-99
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Supervisor: Dr. Ria Reis

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ACKNOWLEDGEMENT

I wish to thank my supervisor Dr. Ria Reis for her supervision and critical support during the field work and the writing of the thesis. I also wish to thank Dr. Corlien Varkevisser and Trudie Gerrits for their help in developing the proposal of this study. I profited from the comments offered by my fellow AMMA students too. I am in debt to Ruth van Zorge who shared her unpublished research findings which gave me an overview of the field of epilepsy in the Netherlands. I wish to thank Dr. Harry Meinardi, for giving me time to introduce me to the activities of the epilepsy institute. I am grateful to Ms. Adri Bader, Ms. Moor Cooper and Mr. Siebe Dijkstra for their help in finding respondents. I am indebted to all my respondents for their enthusiastic cooperation. Thanks are due to Heidi Arendsen for her help in interpretation during interviews. I specially wish to thank my husband Shahaduzzaman for his valuable comments and editorial help. It would not have been possible to write this thesis if he wouldn't have relieved me from the responsibility of taking care of our two and half years old child. I enjoyed my field work in the Netherlands and I look forward to continue research work on socio-cultural dimensions of epilepsy in my own country.

The NUFFIC provided the fund which made it possible for me to attend the Amsterdam Master's in Medical Anthropology (AMMA) and to carry out the research on which this thesis is based.

Amsterdam 12 August 1999
ABSTRACT

The aim of this study was to explore the effect of epilepsy on the reproductive life and self image of Dutch women with epilepsy. It was intended to investigate how this effect takes shape in a technologically advanced and economically developed society like The Netherlands. The study was explorative and made use of qualitative methods. The thesis is based upon in-depth interviews with twelve Dutch women with epilepsy and with three key informants. Additional sources of secondary data were also consulted. The findings reveal that in spite of tremendous medical technological advancement and social development in the Netherlands epilepsy still may negatively influence the reproductive decisions and the self image of the Dutch women who suffer from this disorder. On the other hand women with epilepsy possess a highly positive attitude towards life. It was also found that the organisations working in the field of epilepsy are not gender sensitive. Based on the findings specific recommendations are made.
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CHAPTER - 1

INTRODUCTION

Epilepsy is a disorder surrounded by myths and misconceptions. Not only can epileptic seizures be unpredictable and disruptive, but they are also widely regarded as evidence of stigma. Epilepsy can set people apart from others. Whilst medicine has made great progress in the diagnosis and management of epilepsy, the social and psychological consequences for the individual have until recently been neglected. (Scambler.1989)

The Dutch celebrity Van Gogh is one of the famous sufferers of epilepsy but there are thousands of other Dutch persons who have suffered or are suffering from epilepsy whose name we don’t know. A recent World Health Organisation report estimates that 0.5-4% of any population will experience epilepsy (WHO 1990). The prevalence of epilepsy in the Netherlands is estimated at 1 in 150 persons (1.5%), which means that approximately 90,000 Dutch are suffering from epilepsy (Instituut Voor Epilepsiebestrijding/ IVE). This study tries to listen to the voices of Dutch women who are suffering from epilepsy. It deals particularly with the consequences of epilepsy for women’s reproductive life and with the social and psychological reactions that constitute their self image.

Women with epilepsy face epilepsy-related problems throughout their reproductive lives (EFUSA 1999). Reproduction is a crucial area for women’s studies since it is the woman’s body that is responsible for carrying the baby. Women with epilepsy may face extra difficulties when it comes to pregnancy and child birth. First, since the disorder and medication may aggravate and influence the health of mother and child. Secondly, because the woman with epilepsy who may already be suffering from lack of independence and self esteem may feel constraints between the
sick role of care receiver and the gender role of care giver to the baby. Also the disorder might affect the reproductive decision making or the responsibilities of motherhood. Finally it may conflict with gender role based expectations not only from the women themselves, but also from their families, their work place and the society at large (Jay 1997). This study explores how this tension between the consequences of illness, personal desire and social expectations are dealt with in a literate, technologically advanced and economically developed society, such as The Netherlands where women are expected to be empowered.

The first chapter of the thesis will give background information and discuss the statement of the problem and the objective. It will also give operational definitions, dwell upon the limitation of the study and describe the methods used for the study. The second chapter will describe the profile of respondents and their disease history. The third and fourth chapters will present the major findings of the study regarding the consequences of epilepsy for the reproductive life and self image of Dutch women. Chapter five will contain the discussion, whilst chapter six will present the conclusion. The annex includes the research tools.

1.1 BACKGROUND & STATEMENT OF THE PROBLEM

In discussions of epilepsy it is important to distinguish between epileptic seizures and epilepsy itself. An epileptic seizure is the product of an abnormal irregular discharge of cerebral neurones while epilepsy itself is defined as a continuing tendency to epileptic seizures. Epilepsy is therefore viewed as a symptom rather than a disease (Scambler 1989: 1).

Individual illness consequences depend on the type of seizures; hence it is important to mention the different types of seizure. Epileptic seizures can take a number of different forms depending on
the site of the abnormal neuronal discharge in the brain. If the discharge remains confined to one part of the brain, the resultant seizure is described as a partial seizure. If the abnormal discharge begins in one part of the brain but subsequently spreads to all parts, the seizure is said to be a partial seizure with secondary generalisation. Sometimes the abnormal discharge originates in the mesodiencephalic system and spreads more or less simultaneously to all parts of the brain. Such a seizure, generalised at onset, is known as a primary generalised seizure. Several hundred forms of epileptic seizures have been recorded; among them three types of seizures are seen frequently, they are:

- the grand mal or the big seizure, with a so-called spasm (tonic) of the whole body; followed by rhythmical shaking (clonic) of the limbs and the head, all at complete unconsciousness;
- the absence, with a loss of consciousness lasting for only a few seconds; and
- the complex, partial seizure (formerly called psychomotor seizure) with both reduced consciousness and a number of involuntary actions like groping and rubbing movements with the hands, walking around, lip smacking and swallowing movements.

There are several known causes for epilepsy, and genetic factors contribute very minimally to the totality. Congenital malformations, present at birth and inherited also may cause epilepsy. Brain tumours may cause epilepsy mostly by damaging the neighbouring neurones. Certain infectious diseases like bacterial meningitis, encephalitis and bacterial brain abscesses and a number of parasites for example malaria also may cause epileptic seizures. Epilepsy can also be caused by hypoglycaemia (low blood glucose concentrations and hypocalcaemia (low serum calcium), especially in the new born. In adulthood, other acquired metabolic diseases like chronic renal failure can cause seizures. Apart from all these, chronic alcoholism can result in the loss of
cerebral neurones and thus cause epilepsy. Some degenerative disorders like Alzheimer's disease or pre-senile dementia are associated with epilepsy (Scambler 1989: 5-7).

The main treatment for epilepsy is by drugs. A majority of people with epilepsy can be rendered seizure free by pharmacological means. In a small proportion of persons with epilepsy surgery is seen as an appropriate means of control for seizures. With the blessings of effective modern bio-medical treatments, it is possible to prevent seizures entirely in the majority of people with epilepsy (Scambler 1989: 7-10).

In Netherlands if someone appears to have seizures, the person will first go to the general practitioner who would refer to a neurologist or a paediatrician depending on the age of the person. In most cases the person will need no further referral, as it will be possible to control the seizures at this point by means of drugs. In case the seizures keep coming back or if the epilepsy is accompanied by problems which are not purely medical, the persons may be referred to one of the special epilepsy outpatient clinics run by one of the three epilepsy centres, the Dr. Hans Berger Clinic in Breda, the Kempenhaeghe Foundation in Heeze and the Instituut voor Epilepsiebestrijding in Heemstede. These outpatient clinics have a bureau for social service attached. By working together the outpatient neurologist and the social worker may assist in solving the complex problems caused by epilepsy. Sometimes, for instance when it is not clear whether the individual indeed has epilepsy the specialist will also refer the patient to the epilepsy centre itself. Some patients with complex problems will be admitted to an epilepsy centre for more intensive guidance and treatment, either to determine the right medication, or for psychosocial support. Psychiatric problems, expressing themselves in phenomena resembling epilepsy, also require admission to one of the three epilepsy centres in the country. The epilepsy Institute in Heemstede, provide special counselling for women with epilepsy and her family members
regarding the possible effect of epilepsy on pregnancy and its management. However, apart from this there is no special program focused on the reproductive health of Women with epilepsy (WWE). If women face problems in this field, they are treated as individual cases.

People with epilepsy in Western countries such as the Netherlands seem to be able to lead normal lives like other people without epilepsy. Public information campaigns in Western societies have improved public attitudes toward epilepsy sufferers; most (Individual with epilepsy) IWE avoid serious psycho-social problems (Kleinman at. El. 1995: 1325). The national epilepsy fund (NEF) in the Netherlands sponsors special costs for patients that are not covered by the insurance. Discrimination in employment for the disabled people has been reduced in different sectors (personal communication; key-informant).

However, this generally positive picture might be different if it is situated into the frame of women’s life. Since social and cultural roles are defined by gender, it is needed to address the wider question: what is it like to be a woman in the context of epilepsy?

Until recently chronic illness as such has received little attention in medical anthropology as a topic of research (Robert and Becker 1993: 281). Research on epilepsy seems to be particularly biomedically oriented. The topic list of scientific research at the institute for Epilepsy (IVE 1996) indicates that social science research on challenges or coping strategies, particularly on gender issues have not been carried out. As Trimble (1991: 33) admits, no literature’s seems to be available on the topic of the position of women with epilepsy. A report on special centres for epilepsy (Meinardi and Pachlatko 1992) which highlights the work done in the different centres of Europe using Netherlands as an example, failed to report the sex of the patients. Since gender
roles and sick roles are culturally constructed, it may be assumed that these would also affect the manner in which epilepsy is experienced by women.

A recent study by Reis (1999) on the relationship between images of epilepsy and conceptualisation of the identity of people with epilepsy, though it does give some examples of living with epilepsy as woman, discusses epilepsy and self among the Dutch only in non-gendered terms. In view of the apparent lack of information, the students of Amsterdam Masters in Medical Anthropology (AMMA) carried out a rapid appraisal exercise on gender differences in the experience of epilepsy in the Netherlands (Unpublished: 1998). It is clear that research in this area is still in its nascent stage. Therefore women with epilepsy and their reproductive health matters particularly in the area of reproductive decision making, including their self image is chosen as focus for this study.

1.1.1 Possible Reproductive Health Problems Associated with Epilepsy

To understand the social relevance of this topic some insight in the effects of epilepsy and anti-epileptic medication on women’s biological processes is needed. A search of biomedical literature revealed scattered information on various aspects. For one thing it is clear that reproductive dysfunctions are common and wide-ranging in women with epilepsy. These dysfunctions may be due to psychological, pharmacological or physiological factors (Morrell 1998). Both epilepsy and the medication can have important effects on the woman's body, on puberty, menstruation, sexuality, contraceptive efficacy, pregnancy, fertility, foetal development, breast-feeding and menopause (El-Sayed 1998, Morell M. J. 1998, Ito-S at. el. 1995, Meinardi
and Pachlako 1992). The effects of epilepsy and medication on women’s reproductive health are elaborated below.

The course of epilepsy in women during puberty and the relationship between seizures and menstruation is influenced by ovarian, pituitary and other hormones, and is largely dependent upon their interrelationship with serum anticonvulsant levels (M.R. Trimble 1991: 56).

Women with epilepsy may suffer from catamenial seizures, seizures that tend to occur mainly premenstrually. Menstrual cycle disruption, anovulatory cycles, disturbances in hypothalamic and/or pituitary hormones and disturbances in gonadal steroids are more common among women with epilepsy than in women without epilepsy (Morrell 1998).

Medication of epilepsy reduces the contraceptive efficacy of the pill and may cause regular vaginal bleeding. If oral contraception contains a high dose oestrogen (50ug) a pill is recommended with an enzyme-inducing anticonvulsant because these pills increase oestrogen metabolism and therefore may create problems (IMJ 1997).

Fertility rates among women treated for their epilepsy are 33% lower than the age-specific national rate (Schwartz-LB 1998). This phenomenon has usually been attributed to the increase of medical and socio-economic problems among the individual with epilepsy (IWE). Long time use of anti-epileptic medication of epilepsy can be the cause of infertility; reduction of fertility in women with epilepsy has been confirmed (Nappi at.el. 1994).

A study investigating whether women with epilepsy are at risk for sexual dysfunction, found that 48% of out patients undergoing surgical treatment for epilepsy report difficulties with sexual functioning. (Morell and Guldner 1996: 1204). Among women with epilepsy (WWE) sexual dysfunction can present as either disorders of desire or physiologic arousal, but the most common dysfunction appears to be an inadequate initial physiologic arousal response (Morell 1998). The
other point is that fear of having a seizures during intercourse is very commonest fear for women with epilepsy (Trimble 1991: 43).

A recent study in New York about the effect of menopause period itself among women with epilepsy found that 23 of the 35 women questioned reported having more seizures during menopause than they experienced previously (EF-USA 1999).

A study on initiation and duration of breast-feeding in women taking antiepileptics, shows that 50% of them choose formula feeding initially which is significantly (85%) less than the control group. Even when they choose breast-feeding initially, its duration is shorter than usual (Ito-S. at al. 1995). Breast feeding is usually safe when the mother is taking anticonvulsant. However, phenobarbitone, primidone and ethosuximide cross in high doses into breast milk. For this reason, breast feeding is usually contraindicated with phenobarbitone. But the mother can breast feed while taking the other two medications provided that the baby is supervised closely for signs of lethargy, sedation and poor feeding (IMJ 1997).

Carrying a baby whilst suffering from epilepsy is a crucial decision for a woman. Despite enormous medical and social advances, western women with epilepsy may still remain at risk for various complications for themselves and for their offspring (Kibria 1992). Although a recent study reports that the majority of women with epilepsy, with ‘appropriate pregnancy planning’ and ‘proper management’ can have a good pregnancy outcome (El-Sayed 1998), there are many factors related to reproductive dysfunctions that may make decision making in the field of reproduction difficult both for women patients, their (potential) partners and their doctors (Yerby 1993). For instance, a recent study (IMJ 1997) in Ireland shows that women with epilepsy are less likely to become pregnant than women without epilepsy. Reasons listed for this are complex: Sexual dysfunction, menstrual disturbance, endocrine problems are reported to be more common
but psycho-social factors are also considered important, as a woman with epilepsy is less likely to marry and may limit her family size because of her illness. It is commonly understood that women with epilepsy are at high risk for complications during pregnancy and also for delivery (Swartjes 1998, Olafsson- at. el, 1998). Pregnancy itself increase the frequency (34% higher) and severity of seizures and complications (Devinsky and Yerby 1994, Yerby 1992, Trimble 1991: 57). Maternal seizures also appear to be disadvantageous to the foetus, increasing the risk of miscarriage, premature labour, intracranial haemorrhage and perhaps, developmental or learning difficulties. There is evidence to suggest that anti-epileptic drugs increase the risk of major malformations (2.4% higher than in the general population), minor anomalies, neonatal haemorrhage and delayed foetal growth and development (Drug and Therapeutics’ Bulletin; 1994, Trimble 1991: 57). A higher risk of spontaneous abortion among women with epilepsy has been proved (Schupf, et. al, 1997). Therefore it is obvious that both medication and seizures have the potential to cause difficulties in women’s reproductive health.

1.1.2 Social and Psychological Consequence of Epilepsy

Apart from these measurable effects on biological processes epilepsy may have several social and psychological consequences too. Epilepsy can be defined as chronic illness: ‘a health condition that can be managed but can not be cured’ (Roberts and Becker 1993:281). Therefore social consequences usually listed for any chronic illness are observable in case of epilepsy as well. It may vary from country to country, or from culture to culture, but it is clear that all over the world the social consequences of epilepsy often cause more suffering than the seizures themselves.
Problems may be experienced in the fields of education and employment, personal relationships and, sometimes even regarding the legal position of people with chronic illness (WHO 1997). It is no wonder that chronic illness may be referred to as 'biographical-disruption' (Bury 1982). Social acceptance of persons with epilepsy may be a considerable problem for patients and their relatives (Rigmor and Mogens 1992: 459). In some societies the disorder is highly stigmatised. (Nkwi and Ndoko 1989). Not surprisingly, these attitudes in turn undermine the availability of treatment of epilepsy, especially in developing countries.

Psychological consequences may be unavoidable for some IWE. People with epilepsy might suffer dreadful uncertainty, because they get neither warnings that seizures are about to occur nor have awareness of the seizures themselves. They feel anxious or upset about possible consequences or about the unpredictability of the seizures. Seizures also commonly cause anxiety through their capacity to disrupt normal activities. An added source of worry is that both seizures and their sequel can bring unhappiness in equal measure to others, especially family members (Scambler 1989: 14). Among some IWE great dependence on the parents or overprotection by the parents is observed (Trimble 1991: 33). Some described the form of suffering of chronically ill as 'loss of self' (Charmaz 1983).

Walters and Charles (1997) discuss this issue of unpredictability and anxiety in the live of women with such chronic illnesses. Women with epilepsy sometimes experience more restrictions in daily life by having seizures than seems necessary (Trimble 1991: 36). Husbands of women with epilepsy may want their wives to stay at home and not work outside for reasons of safety. On the other hand staying at home as housewives may be considered by the women themselves as a safer alternative than working outside. However in a developed society such as the Netherlands, where 'gender equalities' and 'independence' are culturally appreciated, being forced to work at home
might also create social and psychological pressure. For it is well known that women's domestic roles can influence their health. Doyal (1995) has noted the "idioms of distress" that reflect feelings of powerlessness and the contradictions women face in their lives. Among women in the West these feelings may find expression in anxiety and depression: complex physical and psychological response to the contradictory and demanding realities of so many women's daily lives (Walters and Charles 1997: 1729).

That such processes are indeed at work in the lives of women with epilepsy is confirmed by Trimble (1991: 33) who found that women with epilepsy who are under the sheltered employment Scheme of the Instituut voor epilepsiebestrijding in Heemstede, lack self confidence and the will to succeed. The author also mentioned that WWE have often had limited opportunity to develop socially. They are often highly dependent. The unpredictability of seizures may add to low self esteem. A study in the UK by undermined Walters and Charles (1997: 1729) shows the unpredictability and the feeling of limited control that marked the day to day lives of many women. This affected the way they saw themselves. Their sense of self changed and their confidence was undermined.

Motherhood may be another complicating factor. It is known that there are tremendous expectations from mothers, who not only have to look after children, but care for the whole family. The problem appreciated for a working mother who is expected to perform duties both at home and at work. But in the light of a seizure disorder, being a woman adds an extra dimension to the problem (Jay, 1997, citation from Dr. Bennett). In the UK, a country with a socio-cultural background comparable to the Netherlands, a recent study found that women with epilepsy (along with some other chronic diseases) report the loss of their jobs (Walters and Charles 1997: 1729).
The question raised at this point is what is the situation of a working mother with a seizure disorder in the Netherlands.

To answer this question we need to have a clear understanding of the challenges imposed on WWE by the Dutch socio-cultural environment and how these women deal with these challenges. In Holland it was customary for a married woman to stay at home, especially when the children are small (M.R. Trimble 1991: 32). Dutch society values child bearing. Eighty percent of Dutch women have children (Liesbeth Wytzes 1999: 7). Caring for a baby is considered an important responsibility of women. Having the condition of epilepsy limits the extent to which a woman may carry these responsibilities. However, an important question is how mothers with epilepsy deal with the new responsibility of child rearing. The impact of epilepsy on the distribution of work in the household and the responsibilities in routine and everyday relationships affect the way people see, think and feel about themselves (Schneider 1988). Studies of accommodating epilepsy in families (Scambler and Hopkins 1988) do not seem to have considered the fact that most caregivers in families are women and that therefore the sick role and its consequences would be different for a woman, as both caregiver and care receiver. For example, the UK study found that WWE faced challenges in their roles as wives and mothers (Walters and Charles 1997: 1730, 38).

Women's family responsibilities as wives and mothers continue to be the primary definition of womanhood. Women are often trapped by the gender role. To be good wives and mothers they must be seen to be managing despite the difficulties they face in meeting what is sometimes impossible. This is what Bernard (1972) called the 'housewife' syndrome. Chronic disease can decrease self-esteem which can also threaten further devaluation such as women's sense of competence as wives and mothers (30). In this respect gender roles (care giver/ 'housewife' syndrome, primary definition of womanhood) may conflict with the 'sick role' of care receiver.
Given the fact that WWE may have adopted a sick role, what remains to be answered is how do they cope with the challenges imposed on them by their new role as mother. In general the question remains in what way this particular ‘self-limiting’ (Jacoby 1994) chronic physical condition influences the personality and lifestyle of a woman who is affected by it in the particular socio-cultural context of the Netherlands. Hence it will be interesting to explore how a particular biological factor and its psychological consequences influences Dutch women’s daily lives and how these women cope with it.

The foregoing discussion of reproductive issues and socio-cultural and psychological consequences which women with epilepsy may face can be formulated in two conflicts:

- Choice of motherhood VS epilepsy related possible reproductive dysfunction;
- Self image VS challenges caused by the epilepsy disorder.

The issues mentioned above present a scenario which justifies the need to establish the perceived and experienced influences of epilepsy on the reproductive and social and psychological life of Dutch women.
1.2 OBJECTIVE OF THE STUDY

The main Objective was to establish the way in which women with epilepsy perceive and experience the influences of their illness on their reproductive life and self image. From this followed more specific objectives,

1. To understand the perception of WWE about the influence of epilepsy on their reproductive life, such as pregnancy, menstruation, sexuality, partner selection, marriage, contraceptive, child rearing.

2. To understand how women perceive the reactions and responses of others to her condition. 'Others' is understood here as including parents, friends, partners, husbands, children, neighbours and organisations for people with epilepsy.

3. To explore perceived gender differences in the experience of WWE.

4. To investigate the perception of the women of themselves.

5. To investigate how various (personal, professional, social, cultural, economic, religious) factors influence the daily life of WWE's.
1.3 OPERATIONAL DEFINITION

Some of the terms used in this thesis need explanation. Following are the operational definitions of three terms that have been used in this thesis.

1.3.1 Reproductive Life

The term reproductive life will be used here in a broad sense. It will include a range of issues related to women’s reproductive life, both biological, psycho-social and cultural. Some of the issues that will be discussed within reproductive life are: pregnancy, menstruation, sexuality, partner selection, marriage, contraception, breastfeeding and child rearing. However, I will also include ideas about child rearing and the concern of working mothers with epilepsy. Emphasis will be given to the reproductive decision making process.

1.3.2 Self Image

The concept of self image also used here in a broader sense. The self image of WWE is composed of their perception of the individual self, perceived reaction of others, which include the reaction of parents, friends, partners, husbands, children, their attitude towards formal support systems, perceived gender difference and perceived changes in life.

1.3.3 Individual with Epilepsy (IWE)

In this study people with epilepsy will not be referred to as patients, but as ‘Individuals with epilepsy’ (IWE) since they do not necessarily experience epilepsy as an illness (Unpublished
report of rapid appraisal exercise AMMA 1998). The abbreviation, WWE (women with epilepsy) will be used to refer to the study sample.

1.4 LIMITATION OF THE STUDY

Before going to the findings of the study I would like to mention some of the limitations of my research.

Because of the time constraint I could not explore the ideas and reactions of the family members and others surroundings women with epilepsy. Further research in to this field could shade more light on social aspects of living with epilepsy.

To get a clear understanding of gender differences among individuals with epilepsy it would be necessary to also interview men with epilepsy. Due to time constraint this was also not possible in the present study.

Finally there may be a respondent bias, in the sense that for practical reasons most of the women in my study are somehow related to different epilepsy Institutes and as consequence they may be more exposed to various information and communication programs. Women beyond this circle might give different responses.
1.5 METHODS

1.5.1 Theoretical Aspects

The study followed both a cognitive and critical anthropological perspective. The aim of the study was to explore the meaning of the disease from the women's point of view, that is how the sufferers themselves and others related to their experiences, perceive and understand reproductive matters in relation to epilepsy. In short, this study explored what it means to be an IWE in the context of womanhood. I also took into account other social and political aspects of the disease, particularly regarding the reactions of family members and in coping strategies related to different social or state support systems.

1.5.2 Study Design

The study was explorative and qualitative in nature and has focused on the micro level, namely perceived and experienced influences on reproductive life and self-image among Dutch women with epilepsy. The study refers to views of women with epilepsy who have children and of those without children.

1.5.3 Data Collection Techniques

The following tools have been used for data collection in the current study:

* In-depth interview
* Key-informant interview
* Consultation of secondary sources.
Validity of the data has been checked by triangulation through the variety in data collection techniques and in respondent types.

1.5.4 Sample

The study has been conducted among Dutch women with epilepsy.

Due to time limitation, the size of the sample was small. Only Twelve women of reproductive age were selected for in-depth interviews. Six of them had one or more children and six were childless. The snowball method was used to find respondents. In addition three key-informant interviews were conducted, with respondents who were either social workers working in the field of epilepsy or a member of a self-help group.

1.5.5 Data Collection

Data were collected over a period of six weeks. The respondents lived scattered over different parts of the Netherlands. As a result it required a lot of travelling to reach the respondents. Most of the respondents spoke English. With some respondents who did not speak English, the interview was carried out with the help of an interpreter. One copy of the research proposal was given to the interpreter to help her understand the research theme and to help the interpreter to explain the objectives to the informants as well as to participate in the research. Secondary sources of data were explored in order to know the policy and laws concerning epilepsy and the information distributed among individuals with epilepsy in The Netherlands. The quality of the data was checked time to time by the supervisor of the study, who acted as a key-informant in this respect.
1.5.6 Data Processing and Analysis

All interviews were tape recorded. In addition field notes were taken. Soon after the interview the data were transcribed. Data were analysed manually. Wherever applicable matrixes, charts, or diagrams are used.
CHAPTER -2

This chapter gives some information on the demographic background of the respondents and on their disease history.

2.1 RESPONDENT PROFILE

First the particulars of the respondents, their age, marital status, number of children, current job are given then the history of their disease is presented below:

2.1.1 Respondents’ Age

<table>
<thead>
<tr>
<th>Age of respondent</th>
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<td>1</td>
</tr>
<tr>
<td>54</td>
<td>1</td>
</tr>
</tbody>
</table>

The above table shows that the age of the respondents ranges from 24 to 54 years. The mean age is 36.25 year. The age of key-informants are not mentioned here.

2.1.2 Marital Status

<table>
<thead>
<tr>
<th>Status</th>
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<tr>
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</tr>
<tr>
<td>Living together</td>
<td>1</td>
</tr>
</tbody>
</table>
Among the respondents five are married, one is divorced, five are living single and one is living together with her boyfriend. Among the singles one of them never had a partner but the others have had boyfriends for sometimes in different periods of their life or were married.

### 2.1.3 Children Status

<table>
<thead>
<tr>
<th>Status</th>
<th>Number of Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>With Child</td>
<td>6</td>
</tr>
<tr>
<td>Without Child</td>
<td>6</td>
</tr>
</tbody>
</table>

Six of the respondents have children and six do not have children. The age range of their children is from 5 months to 32 years. The range of number of children is 1 to 3.

### 2.1.4 Profession

<table>
<thead>
<tr>
<th>Status</th>
<th>Number of Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>University Student</td>
<td>4</td>
</tr>
<tr>
<td>Housewife</td>
<td>2</td>
</tr>
<tr>
<td>Nursery School Teacher</td>
<td>1</td>
</tr>
<tr>
<td>Day care worker</td>
<td>1</td>
</tr>
<tr>
<td>Office Secretary</td>
<td>1</td>
</tr>
<tr>
<td>Office Assistant</td>
<td>1</td>
</tr>
<tr>
<td>Journalist</td>
<td>1</td>
</tr>
<tr>
<td>Works in a shop</td>
<td>1</td>
</tr>
</tbody>
</table>

Among the respondents four were university students, two housewives and the others are involved in various jobs like journalists, school teacher, day care worker, office secretary, office assistant and one works in a shop.
2.2 DISEASE HISTORY

In taking the history of the illness I wanted to know the age of onset of the disorder, type of seizure they suffered from, the current situation concerning seizures and also important incidences around the time of onset of the seizure. I also asked their perception of the cause of the condition.

The disease history was not taken from the key informants. The table below shows the age of onset of seizures of different respondents in the order of minimum to maximum age of onset.

### 2.2.1 Age of Onset

<table>
<thead>
<tr>
<th>Respondents</th>
<th>Age of onset</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>2</td>
<td>9</td>
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<tr>
<td>3</td>
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<tr>
<td>11</td>
<td>28</td>
</tr>
<tr>
<td>12</td>
<td>31</td>
</tr>
</tbody>
</table>

It is obvious from the table that in case of most of the respondents the seizure started at early age of their life and mostly during adolescence (11-19). With some women the seizures started in their twenties or thirties.
2.2.2 Events Around Onset

While enquiring about any important events around the time of onset of the seizures, it proved that two of the respondents got their first attack around the time of their pregnancy. One had the attack in the last month of her second pregnancy and the other got her first seizure two months after the birth of her second child. The time of the first attack of three respondents was related to their menstruation. One had her first attack two weeks before her menarche. The other got her first seizure during her menarche. She was having excessive bleeding since that period lasted for 10 days. Another respondent who had her first attack at the age of 24, found a pattern of relation with her seizure and the menstruation. She had her period after three days of her first seizure, again when she got her second seizure, she had her menstruation just after three days.

For the rest of the respondents the onset could not be related to specific events. One had her first seizure when she was in a music hall, one however had when she was spending holidays abroad, one had her first seizure when she was relaxing on a couch in a weekend, one also had the first seizure when she was sleeping. Everyone had either their parents or partners or friends around when they had their first seizure.

2.2.3 Types of Seizure

Most of the informants suffer both from big and small seizures. Most of them at some time experienced 'absence' in the course of their illness. The duration of seizures varies from several minutes to a few seconds. Among the respondents one has been seizure free for five years, one for six months. One of the respondents was seizure free for the last two and half years but she had a seizure a month before she was interviewed, another is seizure free for eight years but had one
seizure five months before she was interviewed. The rest, that is nine respondents are still having regular seizures. Some have a seizure once in a month, some four to five times a month, and some once in three months.

2.2.4 Perceived Cause

Most of the respondents initially did not relate the seizure with epilepsy. Parents or partners thought it to be either a simple fainting or due to some psychological reasons. When they were taken to the doctor, some were immediately diagnosed as epilepsy and some had to go through a series of tests and experiments before they were diagnosed as having epilepsy. It seems from the responses that the cause of the seizures is unclear to most of the respondents. They did not get a clear answer from their doctors in this regard. Two of the respondents related their seizures with their pregnancy. One said her second child was not in a normal position during delivery, as it was a breech, she had to push very hard which she thinks caused some problem in her brain and finally resulted in epilepsy. Three of the respondents related their seizure with menstruation. Some of the respondents heard from their doctors that they suffer this seizures because of genetic reasons. Doctors of two respondents said their seizures to be idiopathic, which means that there is no medically known cause of the attack. Some exotic causal perceptions were also generated by the respondents. One initially thought it attacked her because she slept in her step sister’s bed who died a year before, though she changed this perception later. The relative of one respondent thought that it might be related to her father’s death, because her father had died just a month before when she had her first attack. One respondent heard from her Homeopathic practitioner that she is having this seizure because one of her ancestors had a venereal disease. One even
thought that she has this attack because she fell down from her bike at the age of one and half year.

2.2.5 Treatment:

Although, the seizures generated very different ideas, every one was taken to the hospital immediately after the attack. Once they were diagnosed they were treated by a neurologist. Most of the women spent sometime in the epilepsy shelter home during their illness career. One of them underwent surgery for her epilepsy. All the respondents irrespective of their present seizure status continue taking medicines. Even those who have been seizure free for several years are still taking medicines. Some of them experienced various side effects. As one respondent says,

"I take five medicines in a day......I can’t do what I want to do, sometimes I see double, I can not go to the traffic (outside home). Sometimes I hear but I can not understand, what people are talking about. These are all because of my medication......I have some strange medication effect, like suddenly my breast gets hot and some emotion with it....my emotion goes up...I cry some days, I am more emotional nowadays because of medication....."

She says “The problem of side effect is greater for me than my attack.” Another respondent also said, “I am more scared with the side effect than the epilepsy itself.” One of the respondent became obese due to medication, she put on 25 kilogram in one and half year. She was in her adolescence at that time so it was a great concern for her. Some respondent mentioned the effect of medicines on their pregnancy and other reproductive matters, which will be discussed later.

Though everyone was taking biomedical drugs two of them also tried homeopathic medicines for results, which also finally did not work. The key-informant mentioned that some IWE also go for acupuncture and magnetic therapy.
3.1 REPRODUCTIVE LIFE

The relation between reproductive decision making and possible epilepsy related reproductive dysfunction is one of the two major focuses of this study. It is already mentioned that the concept of reproductive life of women is used in this study in a broad sense. Issues that range from pregnancy to menstruation, partner selection, marriage, sexuality, breastfeeding, contraception, and child rearing. Particular attention is given to the influence of epilepsy on the decision making process concerning reproductive issues.

3.1.1 Pregnancy:

The narratives of the respondents revealed that epilepsy influenced their pregnancy or choice of becoming pregnant in various ways. Because of epilepsy some women had to give up their plan to be pregnant, some could not have the desired number of children, some had to delay their plan of pregnancy and again some had to become pregnant earlier than they wanted to. It is clear from the interviews that the decision making process developed and changed over the years.

As I asked one respondent who is single, childless and in her late thirties, whether she wants to have a child or did so at some point of her life, she replied:

"Yes, there was a time that I wanted to have a child, but not any more."

She is a women who loves children and always wanted to have a child but only when she was little older than thirty. She said she loved pregnancy. She even once got pregnant, but that was unplanned, moreover it was a tubal pregnancy, and unfortunately it had to be surgically removed.
However, when she reached the age that she deliberately wanted to have a baby, she faced problems in her relationships, and found herself without a boyfriend.

“I got quite depressed. Because you love pregnancy then all is set up but it did not work. And then my boyfriend ran away, I did not have a new boyfriend by that time. But I wanted to get pregnant.”

Meanwhile she was continuously taking anti epileptic drugs and she grew older. At a certain point she realised that due to her medication she runs the risk of very complicated pregnancy. Finally she abandoned the idea of mothering a child.

“Because of the medicine now I have more chance of getting a handicapped child. It was not so much chance a couple of years before. I also have a second chance of getting tube pregnancy. There is a risk of getting abortion in the first three months of pregnancy too. Moreover I am 37 now. So it is too much all together. I don’t want a handicapped child, definitely not. When I was young it was OK. I could have had take a healthy child but not now. Thus I don’t have any child.”

The fear of the consequences of epilepsy on their pregnancy and on their unborn child was evident in all the responses. They all were afraid of the side effects of the medication on the foetus. They were all worried about the possibility of having a handicapped baby, a baby with an open spine or about a spontaneous abortion. The social workers said that the majority of the questions they receive from women is about the effect of epilepsy on pregnancy.

As the one woman remains childless because of epilepsy, another can not have the desired number of children due to her epilepsy. As one woman said she had to limit the number of her children to only one because of her medication. She said:

“We wanted to have more children but the specialist said no, no more child. They said because of the medicine I was taking for epilepsy, it is not good for me and not good for
the child as well. They (doctors) said first one is okay, but after that it is not safe anymore. They said if you want, it is okay but we prefer not to take any risk. Then we said okay, one child is fine.”

In another case the woman had to delay her plan of having a baby because of the heavy dose of antiepileptic drug that she was taking. She states:

“I couldn’t have a baby now because now I am taking 250 milligrams of the drugs. In the year 2000 I will reduce the medicine dose and then I will have to talk to my doctor whether I can take a child. I really don’t know when I can get a child.”

The reproductive decision of another woman was affected by her epileptic condition in that she had to become pregnant at an earlier age than the average age of pregnancy in Netherlands. Because of the possibilities of complications of late pregnancy with the anti-epileptic medication, the woman got pregnant at the age of twenty four, while the average age of first pregnancy is 30 years in Netherlands. The women said, “I would not have taken the baby so early if I would not have epilepsy”.

In the case of some respondents their pregnancy increased the severity and intensity of the seizure. also delivery was problematic in case of some women. One woman reported that she experienced prolonged labour because of her epilepsy. Moreover, the decision of the location of the delivery was also affected by their epileptic condition. Though most of the women preferred home delivery; which is a common practice in the Netherlands, they all had to undergo hospital delivery because they needed special attention during delivery. It is also important to notice that among the six respondents with children four gave birth to a premature baby.

In the discussion respondents were asked whether they think that epilepsy can affect women’s fertility. Every one said they don’t think this to be the case and they have no idea
whether epilepsy has any connection with infertility. They were also asked whether the child can inherit the disorder from them. Four of the respondents don’t think that a child can inherit epilepsy from its mother. Three of the respondents believe that there is a possibility for the children to inherit the disease. Three other women expressed their uncertainty about this issue. Two of the respondents said, even if the child inherits they are not worried about it because they know how to live with epilepsy and they will be able to teach their children. On the other hand two of the respondents mentioned that they would feel guilty if their children get the illness from them.

3.1.2 Menstruation

Nine out of twelve respondents mentioned that they have problems with menstruation and that this is related to epilepsy one way or another. It is also evident from information provided by a key informant that in her experience most of the women with epilepsy suffer from various menstrual problems and that they ask for solutions. It is already mentioned that three of the respondents saw a direct relation between their first menstruation and first epileptic seizure. They had their first seizure around the time of their menarche or during menarche. The rest of the respondents said they observe a pattern of relation between their menstruation and their seizure. One observed that the frequency of her seizures always becomes higher around the time of her menstruation. Another woman said she will always get a seizure just before her menstruation. While one respondent mentioned that whenever her menstruation comes later than the due time she gets relatively more and heavier seizures. To reduce their seizures, two of the respondents had to undergo forced menopause on the advice of their doctor, one through medication and the other by having her uterus removed. Only two of the respondents said they don’t have problems with menstruation.
3.1.3 Partner Selection/marriage

The selection of the partner and marriage are important components of women's reproductive life. It approved out from the life stories of the women that their selection of partners, friends and their marriage are affected by epilepsy in many ways. For some of the women it was difficult to make friends at young age, because they were very much concerned about their epilepsy. One of the respondents said that she was very shy during her adolescence because of her epileptic condition:

"I was shy because of this disease, also my mother was very preoccupied with epilepsy. She said to me when you will get a boyfriend I want to talk to him first, before you tell him about your condition.... I was also very preoccupied and always thought that man does not want me...."

Two of the respondents said they were so busy with epilepsy during their teenage period that they did not have time to look for boyfriends:

"I had no time for boyfriends, I was busy at that time. Not with my study but with my epilepsy. I was just looking for help and was trying to get rid of it.

"I had less contact with people because for a couple of years I used to be so tired of my epilepsy that I just used to sleep."

One social worker said that he has seen many people with epilepsy, who are depressed and suffer from low self esteem and that as a result they fail to make contact with other people, which affect their selection of partners. Epilepsy creates problems in the marital situation as well. One respondent claims her divorce is due to epilepsy. Another respondent mentioned that the
relationship broke up because the man could not stand the seizures. Thus the woman remained single. She states:

"Yes, I am not married because of this epilepsy. I live single. I had a relationship and I also was having many seizures at that time and the man did not like that, so the relation breaks down."

However there are happy stories too. Two respondents said there is no influence of epilepsy on their relationship. Their partner is well aware of the situation and they have accepted it. As one respondent said "the most important thing is that you love each other. It does not really matter if someone has epilepsy or any other disorder".

### 3.1.4 Sexuality

Most of the respondents expressed their concern about sexuality and epilepsy. Some respondents said having a seizure during love making is the most horrible thing that can happen to a woman. One respondent who experienced a seizure during sexual intercourse 2 or 3 times in her life said, she felt most vulnerable at that time. This feeling intensified when the encounter was with a relatively less known person. In some cases she didn’t tell her partner that she has epilepsy and the guys did not react nicely. They thought maybe she is drunk or a drug addict or crazy. She says:

"...at that very moment I hated it. I felt the seizure coming. So I can push my partner but I am naked at that time, no cloths and that makes me more vulnerable. So there is vulnerability from both sides..."

Some also mentioned that as there is a fear of having a seizure during love making the sexual feeling as such is interrupted. One respondent said her boy friend was always afraid that she might have a seizure during love making, as a result their sexual pleasure was hampered. According to one respondent, intercourse might trigger a seizure because seizures usually come after stress. It
happened to her one day. Just after having sex she had a seizure, which lasted very long, so that her boyfriend got worried and called the doctor. After arriving, the doctor asked what she had been doing before having the seizure. She had to tell the doctor about their love making. This was embarrassing for her and she considered it as a loss of her privacy. Another respondent considered the problem from a different angle. She said when she gets a seizure during love making, her boyfriend took the seizure as an excuse to be overprotective to her. She does not like this attitude of overprotectiveness but she cannot avoid it. Another woman mentioned a different dimension of the problem. Because of her regular medication she feels very tired in the evening, as a result even if she wants to have sex in the evening, she cannot. She has to look for other time of the day to have sex, which is sometimes very inconvenient.

However, one respondent said, it never comes to her mind that it can happen during sex. She thinks it is a fun time, so when one has a good time she will not get a seizure and another woman said, she would rather feel secure if she has a seizure during love making, because her husband will be with her, who would take care of her. None of the respondents said they feel any difficulty in their sexual desire or arousal.

3.1.5 Contraceptive

When asked about contraceptives, most of the respondents said that they know from their doctors that contraceptive pills will not work while combined with the epileptic drugs. One does not match with the other. The pill is not effective for women with epilepsy as long they are under medication. They were also informed by the doctor that if they nevertheless want to take the pill then they will have to take either very strong contraceptive pills or very strong anti-epileptic drugs. It is therefore always a big problem for women with epilepsy to take contraceptive pills,
which is the most popular method of contraception among Dutch women. Among the respondents one did not take the pill because she did not want to have so many hormones in her body, while other tried a normal pill with a strong anti-epileptic drug but discontinued for the fear of side effects. Three of the respondents used copper-T. One discontinued because it didn’t suit her and she switched over to condoms. However, another who uses condoms said she is uneasy with the condom because she does not feel hundred percent secure with it. She thinks the pill is the only secure method, but as she can’t use it she has always the fear of becoming pregnant. Among the rest, one uses safe period method and the husband of another chose vasectomy.

3.1.6 Breast feeding

While inquiring about the effect of epilepsy on breast feeding it appeared that out of the six women having children, two didn’t breast feed according to the advice of their neurologists. One woman, who was seizure free for eight years, started having seizure within two weeks of starting the breast feeding. Two women didn’t have medication during the period of breast feeding. However, one woman continued medication during breast feeding, because she thinks as she took medicines during her pregnancy her baby has already become adapted to the medicines when it was in the womb.

3.1.7 Child Rearing:

Rearing the children is another dimension of women’s reproductive life. As it is a socially and technologically advanced society there are various supporting institutions and mechanisms for rearing children in the Netherlands. Men and women both share responsibilities in rearing child.
However, it is a general feeling among the women that in practice child rearing is still mainly the responsibility of women. As one respondent said,

"I think taking care of the child is still a big thing for women here. It is more important than doing a job. Raising children is more women's responsibility."

If that is the case what happens with the woman with epilepsy who has children? Some believe it depends on the type of seizures, that is: some of the individuals have so frequent and big seizures that they have to remain at home. It is therefore a big burden for them if they have to take care of the children at home. However, some respondents think that whatever form of seizure they have, women with epilepsy cannot take care of the baby properly. The unpredictability and uncertainty of seizures is a big problem for a mother with small children. One of the women described an incidence which reflects the danger of the condition:

"Everything is so uncertain. One day I had a seizure, I was lying down unconsciously for three hours. She (her daughter) was two years old. It is not nice when your daughter finds you with blood (She cut her tongue during seizure - P. N.) and other kind of stuff. You cannot move and your child is next to you in a little blanket. I had it again a few months ago with my little daughter (youngest) in my hands. I fell down over my daughter. Suddenly my husband found us; otherwise she was not breathing anymore. She could not cry, she could have died. It was dangerous."

Some women mentioned about the danger of bathing the baby in the bath tub. They feared that if they have an attack during the bath the baby might drown. They therefore ask help for others or give the bath to the baby when others are around. The women also mentioned various day to day problems. Like one day one of the respondents was taking her child to the school and while she was crossing the road, she stopped in the middle of the road. She thought she was walking but
actually she was not, she was seeing things double. It was dangerous situation because cars were all around. She has this effect because of her medication. Another woman said, her children want to go to the beach but they don’t want to go with her because she has epilepsy. She also could not take her children for outing, as a result the children had to stay at home. Some, however, have a positive attitude towards child rearing. As one women said:

“I have taken responsibilities of my own life with epilepsy, I will definitely be able to take responsibility of my child.

One key-informant stated that, decades back it was a common thought that women with epilepsy should not have children. It was thought that people with epilepsy can not raise children. However, things have changed now. She mentioned that it is understandable that as there were not many anti-epileptic drugs available, people had lots of seizures. Therefore it was usual to have such ideas. Now people think that if the mother with epilepsy follows some practical advises she can easily rear her children like any one else. But all these assurances do not always secure women’s mind. As one of the women with epilepsy is carrying this image with her all her life:

“When I wanted to have a baby, I could only imagine one scene in front of me. I see I am having a seizure, people are putting me in the ambulance and the child is alone in its buggy, just in the middle of the street....”

These statements show how the uncertainty of seizures is a great threat to proper mothering and the practical difficulties faced by the WWE in child rearing. On the other hand the statements also indicate that WWE also differ the type of problems in experienced and in their coping strategies.
CHAPTER - 4

4.1 SELF-IMAGE

The second focus of the study is the issue of self image and the challenges caused by the epileptic disorder. To understand the self image of these women, various issues were discussed. The concept of self image is used in a broad context. I explored the perceived reaction of others towards her condition, the women’s attitude towards formal support systems, her perception of her own self, perceived gender differences and perceived changes in daily life. All these aspects comprise the self image of the women with epilepsy.

4.1.1 Perceived Reactions of Others:

One of my questions was how women perceive the reactions of others towards her condition. The ‘others’ include the parents, friends, partners, husbands, and children. Varied responses were found.

Most of the women remembered the reaction of their parents during their childhood and adolescence. Some of the parents got very anxious after knowing that their daughter has got epilepsy, they became overconcerned about the condition. As a consequence they were not allowed to do many things that a child of that age would do. One woman said:

“I could not go to swim, I had to come home very early. While my friends used to stay until 12 o’clock, I had to come back at 9 o’ clock. My life was restricted. My mother used to ask me about my medicine ten times a day”
Some of the women think that their parents were overprotective. As a consequence there was always a conflict between the parents (particularly mothers) and the children with epilepsy. Following comments reflect this situation:

“My mother was overprotective. I could not go anywhere alone, when I used to go to my room and lock it, she would become really upset, really angry. When I look back now to my mother’s attitude I can understand her but at that time it was different. We used to have regular arguments”.

“The seizure influenced my parents more than me. They were very concerned. I did not care about it so much. I wanted to go out and they thought that I will get a seizure. So there was a constant conflict”

However, there were parents who did not restrict the life of their children. Some women said their parents allowed them to have freedom and develop themselves. They could do whatever their friends would do, they were allowed to drink, go out, though there were hidden worries in the back of the parent’s mind. One of the respondents said that though her parents allowed her to stay out late, her mother told her later that she could not sleep until she returned home -

“Just recently my mother told me that she always remained awake in bed till I would return from outside. And when she would see me, she would think well now I can sleep”.

One of the respondents’ parents were not very anxious because her grandfather had epilepsy, so they had previous experience of dealing with epilepsy. They thought that the daughter inherited the disease from the grandfather and they took care of her accordingly.

Most of the women said when they were in highschool, they did not have much difficulty to go along with their friends. One woman said she told her friends and never made a secret out
of it. And the friends took it for granted. However, when the friends first saw the seizure they were very upset because they had never seen such things before.

"That was the first time they saw my attack and they were very upset about it. However, not that upset that they did not want to see me again"

One of the respondents was constantly worried about her chance of getting a seizure at school and the probable reactions of others.

"At that age I was really scared that they might laugh at me. My teacher knew, I had to explain them what they have to do if I get a seizure."

Women said they did not tell about their seizure to friends whom they met briefly or had very short relations with but if they wanted to have a longer relationship they would tell them. One woman said that she befriended people on the basis of how they react to her epilepsy: if someone does not react positively she does not continue her relation with her/him. One respondent said when she first told her boyfriend about her epilepsy, the boyfriend reacted very positively and that was a very new feeling for her because she was always confused about how people will react if she tells them about her condition. That was the first time she somebody about her seizures. She said,

"By telling him I learned how to talk about it because before that I never talked about it. He was the first one with whom I talked about this. I was telling myself if, if he does not want me with seizures, its fine. Then I told him and it was OK. From then I got a different thinking about myself and learned the way to talk about epilepsy".

But women got negative reactions too. As one respondent said-

"Yes, I got lot of negative reactions, when I was young, from the boys and girls at school. You know they are terrible. They made a lot of fun of me. Called me other 'names' because of the seizures. They did act like me when I am in seizure. I got very shy"
Some of the respondents said that reactions towards a person with epilepsy will vary in different parts of the country and also in different generations. Respondents said in big cities in the Netherlands it is not much of a problem, people do not bother, but in villages there are still people who might have different reactions towards epilepsy. As one said,

"There are parts in the Netherlands where people will be afraid of epilepsy and will keep distance. They will think that you have taken alcohol, or you are drug addict or you have a mental disorder."

One respondent even mentioned that in some areas of the Netherlands there is also religious stigma attached to epilepsy:

"In the Netherlands you have a region which is strongly religious. They think that epilepsy is given by god. Lord gives epilepsy because of sin or so. They think nobody has control over seizures. Even it is difficult to speak about epilepsy. I know one child has got epilepsy from that region. Their parents bring him to the epilepsy centre for one year but they did not tell about it in their village"

Hiding the fact of epilepsy to some extent is also found. One kindergarten school teacher said, though she told about her epilepsy to her colleagues, she did not tell it to the kids. She said she did not want to scare them. Another respondent said her children do not disclose to their friends that their mother has epilepsy. Hiding epilepsy in job interviews is also evident, which will be mentioned later on. Key-informants said that from their experience the reaction of people towards epilepsy has changed over time. In the older generation there were misunderstanding and lack of information. But now through television and various other media's people get all sorts of information about epilepsy. They are more aware about the issue and in general people react positively.
The women who have children mentioned the reaction of their children. In the beginning children are generally frightened because they don’t understand why their mother is doing something strange. Later on the women usually tell their children about epilepsy. They explain how to cope with it. Their children are now well adopted to the situation, although they usually have lots of questions about epilepsy. They want to know why it happened to their mother, how it happened, whether they can also be affected by it. One respondents said her nine year old daughter takes the role of care giver when she has seizures. Her daughter is worried and always wants to be with her. However, two of the respondents had a bad experience in this regard. One of the respondents once went to the nursery where her children go to play and she got a seizure there; the children were very frightened. Afterwards she was not allowed to go to the nursery anymore. Another respondent mentioned that the friends of her daughter are not allowed to come and to play in her house because their mothers think that perhaps they are not safe here.

4.1.2 Perceived Gender Difference

I mentioned earlier that men with epilepsy were not interviewed in this study. Therefore it is not within the scope of this research to contrast the experience of male and female individuals with epilepsy. However, I discussed with the women their perceptions of gender differences to further explore their self image. From these discussions it appears that most of the women believe that experiences of men and women with epilepsy differ considerably. They mention physiological and social differences. Most of the respondents are of the opinion that physically women suffer more than men. Because of epilepsy and its medication women suffer from hormonal disturbance, which affects their pregnancy, menstruation and other reproductive matters. The effect on reproductive matters has been discussed in earlier chapter. The relatively heavier burden of epilepsy for women

40
is also expressed in the fact that women have associated themselves with formal support organisations more than men.

One self-help group member said,

"I see more women, women become more close to the association because they suffer more, that is the reason that they come to the association"

According to her, when women are associated with an organisation they are mostly concerned about pregnancy, child rearing and genetic issues of epilepsy while men are found least bothered about these issues. As the social worker stated:

"All these (pregnancy, genetic and so on) questions are asked mostly by women. No men asked such questions. Even if the husband has epilepsy then his wife calls us to know whether his child has the possibility to get that"

While men have other concern:

"Men mostly ask about their sexuality. That is funny or maybe that is their problem in this regard. Sometimes they ask these questions undercover and sometimes more open. Questions from women about sexuality? No, not so often."

It is commonly believed by the respondents that women are more open about their epilepsy than men. Following are some comments in this regard:

"Men have distance, they don’t speak much about it. Women want to know about it, they read more books about it, they go to the neurologist, they will go to the social worker—men don’t want to let others know about it"

"Men use to hide it, pushing it away, they deny it"

"Men can’t express to the outside world while women are more open, they try to explain it to the others"

"I think women talk more about epilepsy than men do"
Respondents related men's tendency to deny epilepsy with the existing male social image.

As one social worker said:

"Male wants to deny because of the macho image. And it is very difficult to help them because when men don’t want to help themselves, then you can’t help. So they face more problems afterwards. That also goes for the social pressure, it is a kind of weakness to admit that there is something wrong with them. Even if they are not allowed to drive they will ask why can’t I drive?? In that case women’s position is better because they admit the problem and want to know what to do."

Another women who thinks that men suffer more than women, mentioned:

"They (men) want to make progress quick. Medicine (for epilepsy) can make people slow, men don’t want to let other people know that they are not quick enough. It creates a cognitive problem, they don’t want to show to the other that they have this problem. Men should be more active, that is what society expects, but when they have epilepsy they are not that active. Society doesn’t accept that much activities from women. So I think men suffer more.

According to one respondent it is also shameful for the men to have epilepsy or to be a father of a child with epilepsy:

"It (epilepsy) is a kind of shame for men while for women it is less shame. Also with the child with epilepsy I think it is more shameful for the father than the mother........men want to be proud of their children, if the child is not complete then it is more shameful for the father, if the child is not OK, you can not show the child to the other. I think it is not so important for the mother.......they are happy with the child whatever they are"

One respondent gave an interesting version of this gender based social acceptance:
"Society is changing but still there is the idea that men should be strong. I think having epilepsy is still a little bit considered as being weaker. You fall on the floor and you move, it is a kind of weakness that men should not show. I think it would be more acceptable if a women has epilepsy than a man having it. It is easier for women that they stay at home, if you are a man and you have severe seizure it is impossible to work outside. If you read literature from the early nineteenth century then you will read that the women are fainting all the time. In the English novels about those rich and wealthy ladies they don’t have to do anything, they walk around the garden and when something happened to them they always faint. Well, this is the view of women, being a weak sex, then you can think that epilepsy is more in line with being a weak women than a macho man. You see when a man faints then he would be considered as weak person but when a women faints then people will say ‘she can’t help it; because she is already like that. It is because of the gender, for man as an individual with epilepsy is weak but as in his gender role he is strong. Women in her gender role is already weak so as an individual with epilepsy she is more weak, which is not a problem.”

Only two of the respondents said that they did not see any difference in experience between men and women with epilepsy.

### 4.1.3 Attitude Towards Formal Support Systems

To understand the women’s self image, I also wanted to know their experience and attitude towards formal support systems for epilepsy, such as the epilepsy institute, epilepsy shelter home or various self-help groups. It was found that all the respondents spent some time in their life at epilepsy shelter home and came across various activities related to epilepsy. They received counselling or information about ‘how to live’ and come to terms with epilepsy. The respondents mentioned the epilepsy foundation and epilepsy institute, which provide treatment as
well as various social and economic support. All of them claimed to be happy with the services they receive from these institutes. Most of them mentioned that they learned how to cope with their illness condition from these organisations. Some of them mentioned that when they were in a shelter home they felt better, because everyone has the same problem, so they did not feel strange there. However, out in all only three of the respondents are actively involved in a self-help group. Explaining the activities of self help groups, respondents mentioned three types of group: patients group, parents group with their children and partners group in which partners of epileptic individuals are involved. Groups are organised so that aspects of epilepsy may be discussed. They talk about how to cope with epilepsy, how to live with it. They discuss with each other is about their problems and how to solve them. They communicate and share each other experiences. Such groups sit once in a week together. After five weeks they stop and start with a new group. The national patient organisation advertises on television and in newspapers to make its activities known. It claims to have now five thousand members, this is the national patient activities. This association also publishes magazines on epilepsy. One of the respondents who is an active member of this self help group said,-

“I am involved with the self help group because I want to know how other people feel to live with epilepsy. Because when I ask the doctor he can say also of things but not with the feeling of someone who has epilepsy himself.”

However the majority of the respondents is not actively involved in the self help group. Among the remaining nine respondents six are passively involved in this kind of groups. They only receive magazines or other information related to epilepsy but they don’t actively participate in meetings. The remaining three respondents are not interested in joining any self help group. They think they are confident enough to cope with their condition and don’t need the help of others. As one of them states:
"I don’t need it, because if I want I can get information. I don’t think I am going to ask people and talk about my epilepsy. I don’t think I need to talk about my epilepsy. I think it is more a matter of self confidence. Lots of women who are not confident enough need to go there. I won’t go there.”

While asked if there is any specific program for women with epilepsy, the key-informants said that there is no program specifically designed for women with epilepsy. They also couldn’t give any gender based information about the IWE in Netherlands. Most of the respondents said they are not aware of such program. Some of them said they don’t think it is necessary to have a separate program for women. However, others said it is important to have a special program dealing with women’s problems with epilepsy. A former director of an epilepsy institute told in a personal conversation that as far as he knows they don’t have any plan to organise any women specific programme for epilepsy, because they don’t consider the IWE in the context of gender.

4.1.4 Perceived Changes in Daily Life

It was also inquired how women perceive the changes in their daily life. The narratives of the women show that epilepsy affects women’s daily and professional life. Due to epilepsy women had to change their life style, pattern of household tasks, home mobility and community mobility, and some had to change their profession. Some made changes in their household arrangements, for instance one respondent had to change the type of bed she uses, and the type of stove in the kitchen. Two of the respondents always keep an alarm in the bedrooms, two women always wear a letter with all the information to help her and to notify her husband, when they are in a public place. One woman always keeps an emergency telephone number tied an her wrist. Another single woman always keeps one set of keys of her home with a neighbouring family. Most of them are
not allowed to drive a car and they also don't usually cycle. All these restrict their mobility in the home and in the community. Some had to change their lifestyle. One sports lover had to stop sport at young age because of epilepsy:

"I am the sporty kind of person, but I couldn't do a lot of sport anymore. I had to stop because of the seizures. I liked to swim but had to stop".

One had to stop her study because she was hospitalised for her epilepsy for a long time, and dropped out of school. She had to start studies again several years later with another batch of students. Some women feel that they are loosing their memory and find it difficult to concentrate as a result of their long term medication. They think that this hampers their day to day activities of life. They can not do house keeping properly. One respondent therefore consider herself as a bad house wife.

In their professional life changes and constraints are clearly observable. Among the respondents some gave up their job because of epilepsy, some had to change their professions, some couldn't choose the profession that they had always wished for; some faced problems in getting a job, some are overburdened with both the job and child care. The following table summarises the professional pattern among the women-

### 4.1.5 Change in Profession

<table>
<thead>
<tr>
<th>Previous status</th>
<th>Number of Respondent</th>
<th>Current Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing</td>
<td>4</td>
<td>Two of them has started further study to shift from the profession. Two of them became house wife.</td>
</tr>
<tr>
<td>Specialist of Disabled children</td>
<td>1</td>
<td>Works in a day care centre</td>
</tr>
<tr>
<td>Shopkeeper</td>
<td>1</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Journalist</td>
<td>1</td>
<td>Works with Industrial publications</td>
</tr>
</tbody>
</table>
One of the respondents who was a nurse in a coronary care unite had to leave her job because she became very slow in action and she tends to forget things, which she thinks to be a side effect of her prolonged medication. Some women left the job after getting a child. Taking care of the children, having seizures and having a job, became too much for them. Four of the respondents said that they could not take the profession they wished for because of epilepsy and they took some other professions instead. They had to adjust and find the kind of job that would fit their condition. Three of the women wanted to become a nurse but two of them were not allowed to study nursing because of their epilepsy, one finally became a office assistant and another a secretary. The other one studied nursing but could not continue. Their comments:

"I wanted to be a nurse but they said that you can not be a nurse, because you have seizures, you can not work during the night, else you might have more seizure. Then I had to choose another job. Hence I had been working for ten years as a secretary."

"I wanted to go to the school of nursing but that was not possible for me anymore because of epilepsy. I had to change my mind, what I wanted to be by profession I couldn’t be that. Then I became an office assistant for accounting but that is not the thing that I wanted to be"

Another woman who wanted to be a journalist also failed to fulfil her desire:

"I always wanted to be a journalist. But working with a newspaper is too difficult with my epilepsy. In my situation it is not possible. Now I am working for a factory, making public relations brochures and making magazines for epilepsy or stuff like that"
Some women mentioned that the job market is limited for an individual with epilepsy, because they need to select a particular kind of job. All the jobs are not open for them and employers are also reluctant in employing an individual with epilepsy. They feel that the employers do not trust the IWE because they are scared about their unpredictable seizure. One respondent mentioned that she wanted to hide the fact that she has epilepsy in an interview for a job. She said,

“It was very hard to get a job when I had my first degree. It is always very important when you go on a job interview to ask yourself the question am I going to tell that I have epilepsy in the interview or am I not? It is really something you have to be aware of. I know from my experience, if they have to chose between someone who have no risks and someone who is taking medication and you have the stamp that you have epilepsy even if you are seizure free for years but you can get it again. And when someone has to make that choice, why should they take the risk? I mean why should they give the job to the person who has epilepsy?”

However, interestingly enough three respondents perceive their epilepsy to have a positive influence in their life also. Two of the respondents think that epilepsy gave them benefit by bringing some routine in to of their life. They feel that because of their disorder they were protected from various bad habits common in this society. For example, one respondent said while most students in their first year use to become drunk, she was never drunk as she controlled herself because of her epilepsy. One woman who works in the organisation that publishes public relations brochures that is associated with epilepsy world. When the woman applied for a job in that organisation, the employers were happy to find her because they observed that they would not have to tell her anytime about epilepsy. The woman thought that it was the first time that she got some benefit from having epilepsy. Getting benefit from epilepsy is an exeption, but generally it emerges from the foregoing discussion that epilepsy has clear effects on the professional life of the women.
4.1.6 Perception of Self:

Along with the other aspects discussed before, one’s perception of one’s self also forms part of one’s image. The respondents were asked, do they consider themselves dependent on others? Do they feel that the life they have is of lesser worth than the life of a person without epilepsy?

‘No’ was the immediate answer of almost all the respondents. Inspite of the various problems that they face in their life due to epilepsy, nobody considered herself sick, dependent or leading a life less than normal life. A strong sense of independence, inspite of their illness was expressed by most respondents. However as the discussion progressed they went deeper into the issue and raised its complexity. Some said they feel very down (depressed) but they don’t know whether it is related to their illness. As one mentioned:

“I don’t have any motivation to do something.......they told me I had identity crisis, that was true, that is because of my personality.......Though I know what can I do and what I can’t but my complain does not go away. Not my tiredness, not the other problems I have........I am not sure if it has something to do with my disease or my personality”

However, the common tendency of most of the respondents was to ignore the illness, to deny it or to say that they don’t care much about it. They don’t complain about it and want to accept life as it is:

Q: Would you consider yourself as a sick person?

A: I have to, because I am. But I don’t want to consider. And I am doing as much as I can.

Another respondent stated:
“I don’t want to talk about it (epilepsy). When I am going to talk about it everyday and think about it then I won’t have a normal live. I want to have a normal life, ......I don’t want to be like that, sitting in the corner and think that , oh......life is going to be terrible.....I have it (epilepsy) right but don’t want to think about it all the day”

This feeling is echoed in other responses too:

“Yes, I am being born with this (epilepsy) I try to think as less as possible about epilepsy”

“I guess that I accepted that I have epilepsy, that I have to live with it also. If I change my life because of the epilepsy I get influenced by it. Then I can not live a normal life. So then epilepsy comes first and afterwards its me. And that is not the way I want to be”

“I don’t consider myself sick because I think you get used to it, at least I got. Well, you can look at things that you are unable to do. But what I can not do, I can not do, that’s all. Everyone has his limits, nobody can do everything.”

None of the respondents said that they suffer from low self esteem. When asked whether they feel themselves dependent on others, everyone strongly denied that. However, some respondents think that it will depend on the personality of the individual. If he or she is not strong enough or confident enough they might feel dependent and blame themselves for their condition. Some said it will depend on the parents too. If the parents are overprotective then the individual will never develop in to a confident person and will not learn to live with his or her condition. A relation was perceived with the types of seizures as well. If the seizures is very big and very frequent then it is difficult for a person with epilepsy to live independently. One respondent, however, thinks that she is dependent on medicine, because if she does not take medicines, she gets a seizure, so to be able to live a normal life she has to depend on medicines. Another
respondent said she has become financially dependent because she had to leave the job. But in general everyone expressed their sense of independence strongly. They said they are independent like any body else and do all the other normal activities that others do.

The social workers and also some of the respondents however pointed out the risks of such perceptions of independence by the IWE. They consider it a denial of the epileptic condition. They observe that some individuals with epilepsy always want to prove themselves and as a result become overactive and over independent, which runs various risks. One social worker said,

“Sometimes this can make people overindependent. There are some children who become overactive. They will say I am not going to sleep tonight. I am not going to go home, I will drink and so on. They want to ignore their epilepsy. It happens quite often. One of our client wants to be a pilot. He wants to prove that he is more than normal. He might want to be a professor doctor, but why pilot, which is an impossibility.”

Another woman with epilepsy recognises this crisis in her own case:

“Doctors and people in general say when you accept the disease then you will feel better. But I can not accept it; not yet. That is the problem.

One social worker summarised the problem:

“You see that there is a big difference between ambition and the possibilities. You will see that those who are fighting against their epilepsy, they don’t like to cope with the epilepsy or they don’t accept epilepsy, sometimes they choose the job to deny the epilepsy. So they like to become a pilot or want to drive a car. These are a little bit too much. They do this
because they want to ignore the epilepsy. So one must be very honest and clean about the possibilities........

When I asked him, why people do like that, he answered said, “because people are complicated creature”

No doubt the issue of the self image of individual with epilepsy is complicated and paradoxical. The whole sense of ‘normality’ gets confused when an WWE who through surgery became seizure free, gives the following comment:

“When you are living with epilepsy then you are living in a small world. After being operated when I did not have seizure anymore for the time being, I felt I have no epilepsy anymore. That was another world for me because I saw the world in a different way. I saw the colour of the flower, I felt like a butterfly, I enjoyed nature; it was natural life for me.......my world has been changed.......I felt like a human being again.”
CHAPTER - 5

5.1 DISCUSSION

The aim of this study was to explore two aspects in the life of Dutch women with epilepsy; the relation between reproductive decision making and possible epilepsy related reproductive dysfunctions and the relation between self image and the challenges posed by the disorder. It was intended to investigate how these relations take shape in a technologically advanced and economically developed society like Netherlands.

Reproductive decisionmaking was discussed against the background of a range of issues related to women's reproductive life. In order to understand the influence of epilepsy on women's reproductive life their experiences with pregnancy, menstruation, partner selection, sexuality, marriage, contraceptive use, and child rearing were explored. Emphasis was given to women's reproductive decision making.

It is obvious from the findings that decision making and the consequences of different aspects of reproductive life of the women are clearly affected by the epilepsy related possible reproductive dysfunctions. In case of most of the respondents, epilepsy had a major effect on decision making and consequences of pregnancy. Experience of the women shows that the ability to become pregnant, the number of children and the timing of pregnancy were directly influenced by epilepsy. In some cases pregnancy increased the number of seizures. Delivery was also complicated for some women with epilepsy. Epilepsy also influenced decisions regarding the location of delivery. Because of their epileptic condition, all the respondents who had children had to deliver in the hospital, though home delivery is the common trend in Netherlands. Moreover, the majority of respondents who had a child had a premature babies. This is in accordance with the

The majority of the respondents see a relation with their menstrual disorder and epilepsy. Either epilepsy causes an irregularity of menstruation or menstruation heightens the intensity of epileptic seizures. Two of the respondents had to undergo early menopause to control their seizures, one through medication and the other by the removal of the uterus. Disease histories also show that a number of respondents had their first attack during their puberty and around the time of menarche. These findings all confirm biomedical data that have established the association of epilepsy with menstruation and puberty. (Trimble 1991, Morrel 1998).

The experience of the women shows that, at least in some cases epilepsy was a factor that interrupted friendship, relationships or caused marriage breakdown, which had a profound effect on their reproductive life. Women had to remain childless because they didn't find their male partners at the appropriate reproductive age. It is also found from the study that sexuality may be hampered in case of women with epilepsy. Having a seizure during intercourse is one of the commonest fear for women with epilepsy. Because of the fear of the unpredictable nature of the seizure and due to prolonged medication some respondents suffered from sexual dysfunction, which was presented as a disorder of desire or of physiologic arousal. This again confirms the research findings of Morrell (1998). The choice of contraceptive is also affected by the presence of epilepsy. It is a pharmacological fact that anti-epileptic medication reduces the contraceptive efficacy of the oral contraceptives. As a result most of the respondents of this study had to change their contraceptive choice. Although the pill is the most common contraceptive method in the

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Netherlands, they had to choose otherwise. Some used copper-t, some used condom or ‘save period’ (periodical abstinence) but these were not always convenient for them. The affect of epilepsy on breast feeding is also evident in the experience of the respondents. The statement of the respondents also shows various difficulties faced by the women with epilepsy in the Netherlands.

One important conclusion of this study therefore is that inspite of tremendous improvement of medical technology and other social developments in the Netherlands, epilepsy still deeply affects the process of the reproductive decision making of women.

The second aim of this study was to explore the relation between the self image of the women and the challenges caused by the disorder. It was proposed to discuss the concept of self image in the wider context of the WWE’s social and psychological life. Issues such as the perceived reaction of others, perceived gender difference, attitude towards formal support system, perceived changes in life and perception of self were explored in this regard. The relationship between the effect of reproductive decision making and self image was also investigated.

The respondents reported varied reactions of the people around them. Parents were reportedly overprotective; husbands, boyfriends, friends shared mixed reactions. Some took the epilepsy for granted, some reacted negatively. There is evidence of abuse by friends in one case. Respondents also reported that people associate epilepsy with sin in some part of the country. There is also evidence of hiding epilepsy from others, particularly in the job place. Nonetheless the social isolation and stigmatisation of individuals with epilepsy is not comparable with the
experiences of individual with epilepsy in many developing countries (Nkwi & Ndonko 1989). The women in my study mentioned a definite change in attitude towards epilepsy over the generations.

Another important finding is that women perceive that there is a obvious gender difference in terms of the expression of and coping with epilepsy. They think that women suffer more in relations to their reproductive issues than men. On the other hand, according to them women are more open about such facts than men. Men want to hide their epilepsy in order to maintain their male social image. Women think that epilepsy does not conflict so much with the traditional gender image of female as it does with that of the male.

Epilepsy obviously also affects the daily life of women. Women feel restricted in their life, and feel they had to change their life style because of epilepsy. There is profound influence of epilepsy on the professional life of the women. Some failed to take their desired profession, some had to change it, some even had to give up their job because of the illness.

There is also a relation between reproductive decision making and self image. Some women felt that they failed in their social role failure and considered themselves unsuccessful mothers. Sometimes the role of mother and children is reversed, when during seizures the children took the role of care giver to the mother.

Though most of the respondents claim that they are completely independent in their daily life their reported experiences contradict with this claim. For one thing it is evident from their narrative that though they are not dependent directly on others for day to day living, they are dependent on
various objects and equipment’s. For example, they are dependent on medicines, some are
dependent on the special note kept on their body while they are in public places, some on alarms,
some even became dependent on particular household materials like special beds or stoves.
Certainly when someone depends on materials instead of other human beings, the sense of
dependence might be lower. This could be a possible explanation of the claimed independence of
the respondents. However, the concept of dependence and independence is complex, as Gignac
and Cott (1998:742) write,

"...people’s values, attitudes, and their ways of coping, as well as cultural norms, societal
values, and political policies have an impact on people’s subjective perceptions of their needs and
ultimately their evaluation of their own and others independence and dependence."

However, the striking finding of this study is that, in spite of the paradox in their sense of
dependence, and also inspite of all their problems and inconveniences in their social, professional
and reproductive life, none of them consider themselves having a life less then ‘normal’. They
think they have as many opportunities and abilities as people without epilepsy. Though deep inside
they know that they are ‘sick’, though they are aware of their vulnerability and they know the
danger of the feeling of overindependence, they all seem to accept their situation in a very positive
way. They are not preoccupied with their medical condition. Whereas there is definitely a
‘biographical disruption’ as mentioned by Bury (1982) that does not seem to affect the self image
of the women negatively. In that sense the findings of this study contradict the discussion by
Charmaz (1983), in which she argues that the fundamental form of suffering in the chronically ill is
‘loss of self’. But in case of the Dutch women with epilepsy in this study, this loss of self is not
prominently observable. Charmaz states in the conclusion that, ‘..those who cannot perform
conventional tasks and social obligations lose the very means to sustain a meaningful life.’ (1983).
But this cannot be applied to the women of this study, because none of them seemed to have lost their meaning of life even after suffering from such a chronic illness for many years. The presence of ‘Housewife syndrom’ discussed by Bernard (1972) is also not noticeable in case of Dutch women. The chronic disease did not devaluate women’s sense of competence as wives and mothers. Some even considered the beneficial effect of epilepsy on their life, in a sense that it structured their lifestyle. It corresponds with the character of a Dutch novel, ‘The Laws’ by Connie Palmén, who considers his illness as his salvation from a rudderless life. (cited in Reis: 1999). The result also does not correspond with the view of ‘powerlessness’ that was expressed by many British women suffering from various types of chronic illness in the study by Walters and Charles (1997). The origin of this typical positive attitude of Dutch women towards chronic illness requires further exploration. However, the unpublished study by Reis sheds some light in this issue. She studied epilepsy and self among the Dutch. She challenges Sue Estroff’s (1993) four processes constituting the construction of chronicity and disability:
“the temporal persistence of self and other- perceived dysfunction; continual contact with powerful ‘others’ who diagnose and treat; gradual but forceful redefinition of identity by kin and close associates who observe, are affected by, or share debility; and accompanying loss of roles and identities that are other than illness related”. By presenting 30 case studies Reis argues that Estroff’s description does not correspond with the experience of Dutch people whose seizures are successfully prevented by medical interventions. She writes, ‘ For the majority of Dutch people with epilepsy, the processes constituting the construction of chronicity as described by Estroff do not seem to take place. Their epilepsy may have been a disruption of their life in the first phase of
the illness, but when they no longer suffer seizures their life will normalise, since it is seizures, the acute phenomena, which are perceived as the core of dysfunction in epilepsy’ (p: 25).

This is in accordance with the present study. However, I would carry Reis’s argument further and would propose that in case of Dutch women with epilepsy the images of epilepsy and conceptualisations of their identity do not differ much between those who still have seizures and those who don’t. The narratives of the women with epilepsy clearly show the various threats to their self image but irrespective of their seizure state, they all successfully maintained an image of a normal, free, dignified human being and try to exercise their opportunities. There is no direct relation between the severity of problems and people’s experience of self worth. The underlying cultural values expressed in the narratives of the respondents give some clue to understand this particular attitude. The sensitivity and acceptance of one’s own limitations, the awareness of human equality, the parallel concept of female gender role and sick role, the value of struggle probably contribute to the typical Dutch positive attitude towards this illness. The contribution of different Dutch organisations working in the field of epilepsy is also significant, because unlike other international organisations, they pay equal attention to the clinical and social/psychological aspects of epilepsy.

We might remember that one of the respondents after being operated said she feels like a ‘butterfly’. But I would say all the Dutch women of this study, even those who are still suffering from epilepsy also have a hidden pair of butterfly wings. They nurture their freedom and possibilities, they want to fly as high as sky. Maybe their wings are little broken because of this illness, maybe the wings are wet with tears but deep inside their heart they all posses the wings of butterfly.
6.1 CONCLUSION & RECOMMENDATION:

This study shows the life of Dutch women in the context of epilepsy. It shows that epilepsy creates special concerns in the life of women who suffer from it. It deeply affects their reproductive and social life. It is also clear that they perceive differences in coping according to gender. On the other hand the women presented a highly positive attitude and a well adjusted life with epilepsy. The Dutch organisations provide a moral and psychological support to the IWE, which may be a possible reason behind the heightened self image of the WWE. On the other hand, it is also revealed that the organisations generally pay little specific attention to the gender issues.

Based on the findings following recommendations are made:

1. Though women with epilepsy maintain a positive image of life, the actual suffering still exists. Some of these sufferings and concerns are very specific to women. The various social organisations that are working on epilepsy do provide some counselling on female reproductive matters, but if we consider women’s reproductive life in the broader context of the issues discussed above, it is obvious that the service is inadequate. It is therefore recommended that these organisations should focus more on reproductive and gender sensitive issues.
2. The present study was an exploratory one with a very small sample size, a broader study is required in this issue.

3. For the benefit of transcultural comparisons I also propose more exploratory study particularly on two themes: a) gender differences in the experience of epilepsy; and b) cultural factors that contribute to the development of the positive attitude typical to Dutch people with epilepsy.
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Walters-V; Charles-N
1997 “I just cope from day to day”: Unpredictability and anxiety in the lives of women.
‘Social Science and Medicine’. Dec; 45 (11): 1729-39
Wytzes Liesbeth


World Health Organisation Report


WHO (World Health Organisation)


Yerby-MS:


Yerby-MS

Annex:

Research Instrument

Guideline for In-depth interview

Thanks giving/ matter of anonymity and interview duration, will be informed to the respondent at the beginning of the discussion.

Basic information:

Research objective will be explained to the respondent clearly.

Name, age, education, marital status/partner, with child, without child, professions, (ambition)

1. The history of the disease:

First experience of seizures: age, time, place, how did it occurs, personal feeling, others reactions.

Frequency of seizures, last occurrence, treatment, perceived causes.

2. Information for the foundation of 'sick role'/ dependency [self esteem]

(a) What kinds of seizures you have? [duration of seizure, duration of recovery] How do you feel after having a seizure? (local terms of seizures).

(b) Could you describe how epilepsy influences your daily life. (c) Does epilepsy influence your independence? [individualistic society/ interference/extra burden in daily life]
© Would you consider yourself as a sick person? Why? why not?

(d) Have you had received extra care from your family during your childhood, what are they? Can this chronic disorder (or extra care) make people dependent to the other? How?

(e) At present do you receive any regular support from your family or from other? In what way, why?

(h) Whether you have any steady relationship, boyfriend, or planning of marriage. Why?

2. Reproductive issues:

Ethnographic explanation- here my focus is to know whether she faced any problem of her reproductive health due to epilepsy or for the medication. If so how that particular problem has had influence on her decision making of reproduction. What are the social, psychological consequences of that decision.

(a) Are there any women’s health related (reproductive) problems one can face due to seizures, or for the medication?

(b) At what age you have got first menstruation? Do you have any complications on menstruation? What kind of, does frequency of seizure differ during menstruation? What did you do on that time (any special precaution)? Does medication or epilepsy has any effect on menstruation?
(c) Have you ever used any contraceptive? Does medication has any effect on your contraception? Did you face any problem, what kinds.

(d) Do you think epilepsy/medication may have influence on your fertility?

(e) Did you breast feed your child? (only for the mother)

(f) Does epilepsy/medication has any effect on menopause?

(g) Does epilepsy has any impact on your relationship with any boyfriend (past & present)? Do you have any partner now?

(h) Does this disease has any effect on your sexual relationship? How, why? [disturb in dating or in sexual experience]

Questions for women without children:

1. Do you have any desire of having child/desire of motherhood? Why do you want child? (Meaning of children). If not why? What is the reason of this decision? Whether this decision comes together or individual.
2. Would your decision have been different if you wouldn’t have this disorder? Why?
Do you think your decision has impact on your family life, partner? How?

3. How children are valued in the Dutch society [importance of children], What is your own opinion about this?

4. Do you think that epilepsy or medication can influence the pregnancy? How? If yes, is it possible to overcome that? How?

5. Did you discuss it with your partner? Could you elaborate the discussion that you had with your partner about the child bearing.

6. Did you discuss this matter with your general practitioner? What are the information you got from them?

7. If you would have a child, what can be the influences of epilepsy on your new role as mother? 
[extra help]

9. Did you talk about this particular issue (pregnancy, child bearing) with anyone? Friends/Boyfriend/family/ doctor. How/why

10. Are you involve with any (epilepsy institute) self-help group? Do they talk anything about child bearing or reproductive issues? What are the messages and extra care facilities do they give?
11. Is there any difference in impact of epilepsy between men and women's life? How?

12. Being professional and having seizures do you think a child can be an extra burden in your life?

Questions for women with children:

1. What are the factors influences your decision making of having baby. Probing list [Whether this decision comes together (with partner) or individual. Did you have desire of motherhood? Does society desire you to be mother. social pressure, partner pressure or self pressure (to make yourself able to do everything)]

3. Have you faced any influence of epilepsy/medication during the pregnancy? (If yes) how did you overcome this problem? How? [influence in case of others WWE]

2. Do you think your decision of having child has effect on your family life, partner?

3. Did you get support from any agency, or others during your pregnancy? How doctors, midwives, GP co-operated with you during your pregnancy? And in delivery. Is there any organisational support facility? Self help group or Gov. policy?
4. Does epilepsy have any influence on your child rearing [extra help, difficulties, care giver care receiver role conflict]? How do you feel about it. How the responsibility of child care distributed in your family?

6. Do you discuss with your child about this matter, how do you feel to discuss it? how is the reaction of your child? Do you think epilepsy may influence your child’s life. How?

7. Being mother and professional do you feel any influence of seizures on your daily life? (Only for the professionals) What are they? How do you cope with them?

Permission of coming back again if necessary/ Thanks giving