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**“Exploring the burdens and needs of
parents caring for a child with Rett
syndrome”**

Master Thesis

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Abstract

Introduction: Caring for a child with Rett syndrome is afflicted with special challenges for caregivers and also with restrictions in everyday-life.

Aims: Available studies focus on life situations of parents with disabled children in general. This study specifies disease-specific burdens and needs of parents who are caregivers for a child with Rett syndrome. Giving affected parents a voice raises awareness in the society but also in care providers. It highlights possible scarcities or opens up scope for improvements. On long term changes in parental support can save costs for the health system by improvement of their health status.

Methods: A qualitative study based on the phenomenological approach was conducted. 15 parents out of 8 different German federal states were interviewed by telephone. Analysis was done according to summarizing content analysis (Mayring 2007).

Results: Potential burdens and needs were identified in the areas of **everyday-life** (care, communication, mobility structural circumstances, accessibility), **formal support and strains** (late diagnosis, information, behaviour of medical staff, care-facilities, health insurance benefits, allocation to care levels, schools), **financial situation** (labour situation, care allowance of parental nursing care, additional costs), **personal health** (time for recreation, psychological and physical situation), **social and familial support and strains** (leisure time, societal acceptance, guilt & reproach, familial acceptance, impact on siblings, partnerships and friendships), **coping strategies** (open-minded approach, avoidance of confrontation, social awareness) and **prospects** (release, fears of the future).

Discussion: Findings are mostly congruent with literature on caregivers with disabled children. But disease-specific challenges were identified: The challenge to accept that the previously healthy child will lose most of its motor skills and the lacking speech skills which makes it hard to communicate with the child.

Limitations: Parents not organized in parental self-help groups and immigrants are underrepresented. Affected children of interviewees are of different ages and have different disability severity indices. They are therefore hard to compare.

Keywords: Rett syndrome- disabled children- caregiver - disability-related burdens

Acknowledgements

The present master thesis complements my master studies in health sciences at the University of Applied Sciences in Hamburg. By exploring burdens and needs of parents who are caregivers for a child with Rett syndrome I hope to raise awareness for this disability and also for the challenges affected parents have to cope with in their daily life. To conduct research on this topic was my personal desire because I had the privilege to meet a girl with Rett syndrome and her family before I started to plan my master thesis. This experience and the way the family members cope with their situation impressed me a lot and inspired me to conduct this study. I hope that the interest I have in this disability also spreads to the readers.

I would like to thank all people who supported me during the development of my master thesis. However, there are some persons whose support I would like to highlight and to which my special thanks goes to:

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Table of Content

ABSTRACT	I
ACKNOWLEDGEMENTS	II
TABLE OF CONTENT	III
LIST OF TABLES	VII
LIST OF FIGURES	VII
1 INTRODUCTION AND AIMS	1
1.1 Problem statement	1
1.2 Purpose of the study	2
1.3 Structure and composition of the thesis	2
2 THEORETICAL SECTION	3
2.1 Definition of terms	3
2.1.1 The Rett syndrome	3
2.1.2 Needs	6
2.1.3 Burdens	9
2.2 State of research	9
2.2.1 Financial burdens	10
2.2.2 Direct and indirect economic	10
2.2.3 Costs due to housing situation	12
2.3 Emotional burdens and support	12
2.3.1 Rating of overall support	12
2.3.2 Mental and physical well-being	13
2.3.3 Fear of or experienced stigmatisation	14
2.3.4 Lack of time	15
2.4 Formal support	17
2.4.1 Scarcities of different support systems	17

2.4.2	Criticism on health care professionals behaviour	18
2.4.3	Problems with availability and use of short-term services	19
2.4.4	Problem of accessibility of services and support	19
2.5	Familiar strains	20
2.5.1	Restrictions in social activities	20
2.5.2	Disabilities influence on the parental partnership	21
2.5.3	Fear of neglecting siblings	21
2.6	Information and counselling	22
2.6.1	Insufficient education/ information of medical staff	22
2.6.2	Lack of adequate, easy assessable information	23
2.6.3	Lack of experienced, well-educated teachers	24
3	METHODS	24
3.1	Research questions	24
3.2	Research methods	25
3.2.1	Justification of using qualitative research methods	25
3.2.2	Philosophical Assumptions and Paradigm	26
3.2.3	Phenomenological Research	26
3.2.4	Problem Based Interviews	29
3.2.5	Pre-Test	32
3.2.6	The sample	32
3.2.7	Conduction of interviews	36
3.3	Validation of results	36
3.4	Ethical considerations	37
3.5	Data analysis procedures	38
3.5.1	Process of Transcription	38
3.5.2	Summarizing Content Analysis	38
4	DESCRIPTION OF RESULTS	42
4.1	Coping with everyday-life	42
4.1.1	Care as a challenge	42
4.1.2	Communication as a challenge	44
4.1.3	Mobility as a challenge	44
4.1.4	Aspects of accessibility of services	45

4.1.5	Structural circumstances	45
4.1.6	Potential relief	45
4.1.7	Everyday-life of caregivers in a nutshell	49
4.2	Formal support and strains	50
4.2.1	Late diagnosis	50
4.2.2	Disease-specific information	51
4.2.3	Health professionals behaviour	52
4.2.4	Short-term care and fulltime-care facilities	53
4.2.5	Nursing staff	54
4.2.6	Services by health insurances	56
4.2.7	Application for Care Levels	57
4.2.8	School situations	57
4.2.9	Formal support and strains of parents in a nutshell	58
4.3	Financial barriers	60
4.3.1	Labour situation	60
4.3.2	Care allowance of parental nursing care	61
4.3.3	Additional costs	61
4.3.4	Financial barriers in an nutshell	62
4.4	Personal health	62
4.4.1	Time for recreation	62
4.4.2	Psychological situation	63
4.4.3	Physical situation	64
4.4.4	Personal health of parents in a nutshell	65
4.5	Familial and social support and strains	65
4.5.1	Time for leisure/social life	65
4.5.2	Societal exposure to the disability	66
4.5.3	Guilt and reproach	67
4.5.4	Acceptance of the disability	69
4.5.5	Disabilities´ impact on partnerships	69
4.5.6	Disabilities´ impact on siblings	70
4.5.7	Disabilities´ impact on friendships	72
4.5.8	Family & Social Situation in a nutshell	73
4.6	Coping strategies	74
4.6.1	Open minded approach	74
4.6.2	Avoidance of confrontation	76
4.6.3	Societal awareness	77
4.6.4	Coping strategies of parents in a nutshell	77

4.7 Prospects	77
4.7.1 Release of the child	78
4.7.2 Future thoughts	79
4.7.3 Parents' prospects in a nutshell	80
4.8 Summary of Results	81
5 DISCUSSION	86
5.1 Interpretation of Results	86
5.2 Weaknesses and limitations	88
5.3 Expectations	89
REFERENCES	91
STATUTORY DECLARATION	102
APPENDICES	103

List of Tables

Table 1	Time consumption of activities	15
Table 2	Demographics of participants	35
Table 3	Categories and sub-categories	41

List of Figures

Figure 1	Pyramid of Maslow	7
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1 Introduction and aims

1.1 Problem statement

Caring for a child with physical or psychological disabilities provides challenges for affected parents (Anderson et al 2007). Trying to combine the complex requirements of child care with the requirements of daily life is a day to day challenge. There is a multitude of scientific literature and studies available, which focus on the quality of life of affected children. However, few studies have been published on the life situation of their parents. These already existing studies mainly focus on the situation of parents caring for a child with a specific disease or disability (mostly autism or cerebral palsy) or disabilities in general. They show different factors which are considered problematic in their situation as care givers: financial and emotional burdens, restrictions in formal support, familiar strains as well as insufficient information and counselling are mentioned as factors influencing the parental well-being and challenging mental and physical health. However, there are disabilities which have not been further researched in this respect: an example is the situation of parents who are care givers for a child with Rett syndrome. Having a look at this disability, it becomes obvious that there is a lack of literature concerning the burdens and needs of parents caring for a child with this kind of developmental disorder. In the Year 2007, the regional branch north of the German self-help group for parents having a child with Rett syndrome tried to initiate and finance such a study for the first time in cooperation with the faculty of curative pedagogy at Cologne University. However, that project failed because the regional branch withdrew its application during the discussion at the annual general meeting 2007. Reasons are on the one hand that not all members were supporting the project; on the other hand the application was presented under time pressure on this general meeting which was followed by an emotional discussion and disclosure of different opinions on this application. Based on this discussion a revision of the application was contemplated aiming to create a common base for an approval by the members. However, this effort failed. Reasons for critics were for example the allocation of funds and the negation of the utility of such a Rett-specific study.

Certainly, there are a lot of studies already existing which focus on the situation of parents of disabled or chronically ill children. However, the Rett syndrome is a very complex disorder because it is a gradual process with a special challenge: the mother delivers a healthy child and parents live with this assumption for about 6 to 18 months before the development of the physical and mental constraints of the disability start. Therefore, this study should serve as an exploration of the situation of affected parents and provide a basis for relieving conclusions.

1.2 Purpose of the study

The purpose of this phenomenological qualitative study is to strengthen the awareness and understanding of what it means to be the caregiver for a child with Rett syndrome. Furthermore, it should sensitize the environment and affected institutions, professionals and support systems. By giving parents a voice, possible needs and burdens should be identified and interpreted as a further step. By exploring the parental situation and the associated disease specific and general problems in the provision of care in depth the study may enhance the parental situation as well. Showing possible burdens in care and support as disease specific may draw the attention of care providers to potential scarcities or opens up scope for improvements. Furthermore, calling attention to the parental situation and therefore to their health status may have positive long term effects on costs in the health care system conditioned by psychological or physical constrictions due to considerations of changes in supply.

1.3 Structure and composition of the thesis

This assignment is divided into a theoretical section (chapter 2 and 3) and an empirical section (chapter 4 and 5). After a short introduction in **chapter 1**, **chapter 2** describes the definition of the “Rett syndrome”, the state of research and clarifies the terms “burdens” and “needs”. The empirical section starts in **chapter 3** with a description of the methods applied in this study for data collection and data analysis. This section also includes a definition of research questions, the justification of the use of a qualitative research approach and in-depth information about phenomenology and phenomenological research. Moreover,

ethical considerations will be specified. The data analysis according to the hermeneutic phenomenology of van Manen (1990) and the preparation and process of the interviews will be described. In **chapter 4** findings will be described and summarized. As a first step demographic data on the participants will be presented followed by the description of the identified categories and resulting main categories. **Chapter 5** starts with a discussion of the results, their interpretation and critical reflection. Limitations of the study as well as some ideas about future expectations complete the section. The appendices contain the complete interview guideline, an example of the process of paraphrasing, generalisation and reduction and a table with the category system developed by using the summarizing content analysis according to Mayring (2003).

2 Theoretical section

2.1 Definition of terms

In this chapter, the developmental disorder “Rett syndrome” will be described including its symptoms and progress, diagnosis and therapy. Furthermore, the terms “burdens” and “needs” will be discussed.

2.1.1 The Rett syndrome

The Rett syndrome is a severe developmental delay which nearly exclusively affects girls and has a prevalence rate of 1:10000 to 1:15000 (Dobslaff 1998). Annually 50 children come down with Rett syndrome in Germany; it is the second leading disability in girls after the Down syndrome (Rett Syndrome Research Trust). Currently, there are 2000 to 3000 girls and women living with the Rett syndrome in Germany (Rett Syndrome Research Trust)

The disability is counted among the autistic spectrum disorders and has been discovered in 1965 by the Austrian psychiatrist Andreas Rett as a genetically caused, dominantly bequeathed disease which results in severely mental and physical disabilities. At the same time the Swede Hagberg discovered the same clinical picture. Although the syndrome gets more attention since Hagberg published an article in which he diagnosed children with same symptoms, he

abstained from nomination of his name. This is why the disability is called Rett syndrome (Hunter 1999).

The responsible gene for this disease is called *MECP2* and its mutation is found in 95% of the affected children (Bourdon et al 2001; Schollen et al 2003). The *MECP2*-gene is located on the x-chromosome. It can derive from both, mother and father. However, analyzing the genes of the parents mostly shows no abnormalities. Rather the mutation arises anew in the uterus. In some cases the mutation is caused by the generation of the egg cell. Boys, who don't receive an x-chromosome from their fathers but only the y-chromosome, are rarely affected by the Rett syndrome. The chance that a second child in the family is affected by the syndrome is below 1% (Kwon 2011).

Most of the affected persons will not speak and only 50% will walk in their adulthood. They remain severely restricted in their mental and physical abilities as well as in their communicative competences (Elternhilfe Rett-Syndrom 2013). Generally life expectancy is only slightly reduced by the disability itself. However the average life expectancy is about 40 years because premature death is often related to seizure, pneumonia, malnutrition, or accidents (Kwon 2011) but 24 hour care throughout the whole life is required (Elternhilfe Rett-Syndrom 2013).

Symptoms and progress

All affected persons show the same clinical attributes; especially the so called hand stereotype is typical for this disease. After a usually normal pregnancy, there are no abnormalities, initially. At later date seclusion, diminished growth of the head, a loss of abilities which had already been acquired and a considerable dysfunction of speech development appear. Many affected children do not learn how to walk or are restricted in their physical abilities. Typical accessory symptoms are scoliosis, epilepsy and respiration abnormalities (Witt Engerström 1990). The disease proceeds in four stages:

First stage (6th to 18th months of life)

A slowdown or cessation of motor functionality occurs. Attention and activity are decreasing. Disinterest in toys, the environment and persons become apparent (Witt Engerström 1990). This stage is oftentimes realized retrospectively (Elternhilfe Rett-Syndrom 2013)

Second stage (1st to 3rd years of life)

This is the regression state of general development. Already learned abilities are lost, for example the functional use of the hands or the faculty of speech. During this stage it often happens that Autism is diagnosed misleadingly. The affected children are socially and emotionally reclusive. Furthermore, unexpected laughing or screaming bouts occur (Witt Engerström 1990).

Third stage (2nd to 10th years of life)

After a sudden and fast onset of regression, the affected children now reach a calm phase. The autistic attitudes abate; they begin to show interest in their environment. The ability to communicate improves. However, apraxia (inability to carry out directed movements), ataxia (a lack of coordination of different muscle groups) and the hand stereotypes are increasing, cramps arise. The insecure walk becomes more apparent; the already existing scoliosis degrades or develops anew (Witt Engerström 1990). In consequence of the serious impairment of the scoliosis, organs can be compromised. This frequently leads to pneumonia, and unclear cardiac arrhythmia. About 80% also develop Epilepsy (Steffenburg et al 2001)

Forth stage (from the 10th year of life on)

The contact behaviour further increases, cognitive advancements become visible, cramps are diminished. However the gross motor skills and the scoliosis are worsened, spasticity leads to an immobility of the affected children (Witt Engerström 1990).

There are different variances of the classical disease pattern:

The congenital type (the syndrome appears immediately after birth)

The early-seizure-onset type (early development epileptic cramps before the second year of life)

The preserved-speech type (speech abilities be preserved partly)

The Late-regression-type (second phase begins after the 8th year of life)

The forme-fruste-type (only a few symptoms are distinctive mild, many abilities persist) (Jacob et al 2009).

Diagnosis

Until 1999 the Rett syndrome was only diagnosed on the basis of clinical criteria, which had been defined and presented by Prof Rett at the international Rett conference in Vienna in 1984. These criteria were written down in 1885, refined in

1988 and are generally accepted as diagnosis for the Rett syndrome (Dobslaff 1998).

Therefore, only severe cases of the disease were detected. In 1998 researchers from the Howard Hughes Medical Institute at Baylor College of Medicine and Stanford University found out that the gene localization of the assumed mutation could be narrowed down to the band 28 of the long arm of the x-chromosome (Xq28) and the responsible gene, MECP2, was found. Since 1999 there is a gene test available this also filters the non-typical cases and allocates them to the Rett syndrome (Elternhilfe Rett-Syndrom 2013). It becomes apparent, that a range of relatively mild forms of the disease exists.

Therapy

So far there is no existing therapy to cure the Rett syndrome. Symptoms only can be reduced by orthopaedic devices, operations or drugs. Supportive therapies are offered to facilitate the everyday life of the affected children. Examples are physiotherapy, music therapy, and horseback riding therapy or supported communication.

2.1.2 Needs

Generally, a need can be described as the desire for abolishing a human deficiency or something which is experienced by an individual as a deficiency (Schwaiger & Meyer 2009). However, there are other definitions of needs which have become popular over the last decades. One of the most famous is the definition of Maslow and the pyramid of needs he developed. Maslow acted on the assumption that people are motivated to achieve certain needs. If one need is achieved, he or she will try to fulfil the next need. He clarified this by means of the Maslow pyramid which organizes human needs hierarchically without including needs which can be fulfilled by economy.

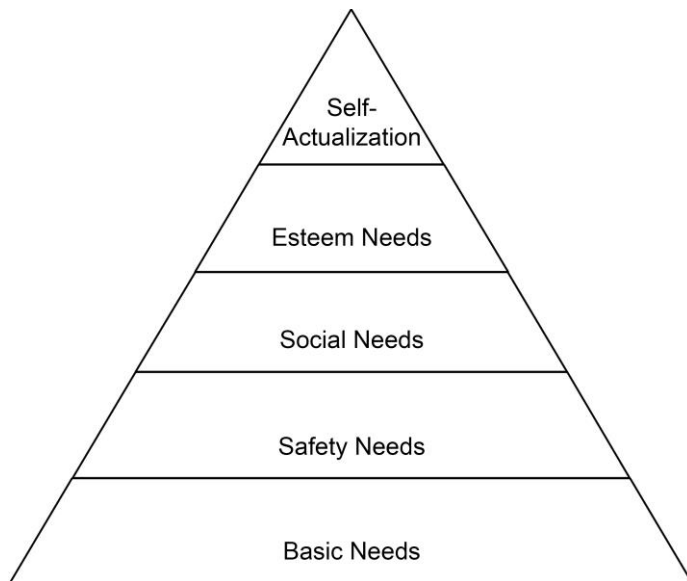


Figure 1: Pyramid of Maslow (compiled by the author)

The figure shows the most commonly used and known five stage model of Maslow. In this connection he divided the needs into the largest stage, the basic needs, which include physiological basic needs like eating and drinking, sleeping, breathing and excretion. The second stage, the safety needs, includes financial safety, availability of a workplace, legal certainty, or the feeling of living in a safe environment. The third stage, the social needs, include love and appreciation, while the fourth stage, the esteem needs, includes strength, status, power, fame and respect. The last stage is the self-actualization which includes the development of the own personality (Maslow 2002). The stages 1 to 3 (sometimes also stage 4 is included) are classified as deficiency needs. These needs have to be satisfied and if they are met they no longer motivate actively for example you do not drink if you are not thirsty. Stage 5 (and sometimes also stage 4) is classified as growth need. An example is the following: a painter paints for self-actualization. However, his need for creativity is not fulfilled after a specific number of paintings.

According to Maslow, one must satisfy a lower stage need before proceeding to meet a need of a higher stage. Every individual is capable and wants to reach the level of self-actualization which is at the top. However progress can be intercepted by break down to meet lower stage needs. As Maslow highlighted only one in a hundred people become completely self-actualized because society honors motivation primarily based on love, esteem or other social needs. However this

classification is a highly regarded model, there is a lot of criticism. The American researcher O'Shaugnessy criticizes the hierarchical composition. He doubts the existence of deficiency needs in western affluent societies (O'Shaugnessy 1987). Another issue is the assign ability of the classification to all humans and all situations. Maslow was a psychotherapist and therefore the base of his model was to a lesser extent empirical research results but rather the experiences with his patients. Furthermore, the top of the pyramid, self-actualization, has been challenged to be only typical for western societies which assign a high societal value to individualism. Also Maslow modified his classification system in the 70ies and separated three growth motifs: cognitive needs include knowledge, understanding and new experiences; aesthetic needs include symmetry, order and beauty and self-actualization include exhausting own potential and finding sense. The highest form of self-actualization for him is self-transcendence.

Another classification of needs is the ERG theory developed by Clayton Alderfer in 1969. He distinguishes between three classifications: **E**xistence, **R**elatedness and **G**rowth. In contrast to the assumption of Maslow that the access to a higher level of needs requires the lower level needs to be met the ERG levels of Alderfer are simultaneous needs. If a long lasting non-satisfaction of a higher ranked need occurs this leads to frustration, there is a throwback to a lower classification motive which intensifies this motive. Thereby Alderfer tries to make the model more flexible and to allow the adjustment to a wider scope of observed behaviour (Alderfer 1969). As an example he mentioned the starving artist, who subordinates a basic need to a creative growth need.

Scientist Hüther has contrary opinions: in his view humans are motivated by new and meaningful or relevant things, according to him the biggest motivators are social factors. From his point of view the brain is not only an organ for thinking than rather a social organ (Hüther 2007).

However, there is a variety of possible classification systems for different needs. Needs are complex and may differ depending on the affected person or situation. This assignment focuses on the parental needs which are linked to the burden of care giving for a child with Rett syndrome and therefore cannot be narrowed down in advance. The needs will become apparent while analyzing the statements of the affected parents with regard to their experience.

2.1.3 Burdens

Families who care for a disabled child perform societal meaningful services which are expected, but not adequately valued by society (Schlack 2000). However, caring for a child with such a severe disability like the Rett syndrome is a burden for parents. Burdens in this work describe all challenges which affected parents have to face and which are afflicted with the burden to care for a child with Rett syndrome. It also includes the daily requirements of care giving under such difficult circumstances.

A disabled child needs in addition to the care requirements during school age care and emotional support and the availability of an attachment figure like a toddler. Long time this care requirements and burdens of basic care are high (Diener et al 1999). Developments of the child's cognitive and functional abilities are oftentimes stagnant. The aging and the afflicted gain in weight additionally can increase the burden of care.

In chapter 3, potential burdens for affected parents have been identified and will be presented. However, they are not adjusted specifically for parents of children with Rett syndrome but generally describe the situation of parents with disabled or chronically diseased children.

2.2 State of research

Little is known about burdens and needs of parents who are care takers for a child with the Rett syndrome. The online database *pubmed*, only provided one article with the focus on this specific topic. For that reason, the search strategy was modified and the literature review was extended to articles dealing with the life situation of parents who are care givers for disabled children in general. Since Rett syndrome is a developmental delay, this search allows inferences to this disability. Below, relevant categories which occurred throughout the reviewed articles are described.

2.2.1 Financial burdens

This chapter summarizes all disability related financial burdens mentioned in the reviewed articles. As main categories direct and indirect economic costs and costs due to housing situation have been identified and will be further described below.

2.2.2 Direct and indirect economic

In large part financial losses are mentioned as a problem which parents of disabled children have to face. As Boyraz and Sayger describe, income has an effect on parental well-being (Boyraz & Sayger 2011). In a nutshell, Sloper and Beresford identify as possible factors which could negatively influence the working situation in affected families high care requirements by the child, numerous appointments with specialists which can also be time consuming, and a shortage of child care support (Sloper & Beresford 2006).

Kuhltau and colleagues as well as Anderson and colleagues reported that 40% of the families caring for a disabled child in the U.S. are experiencing financial shortages (Kuhltau et al 2005; Anderson et al 2007), while Sloper et al assume that about 55% of the affected families are sliding towards poverty due to their child's condition in the UK (Sloper & Beresford 2006). These losses are mostly due to the fact that one parent has to cut working hours or even to quit work completely because of the high burden of care for the disabled child (Sloper et al 2006; Baillargeon et al 2011; Okumura 2009; Anderson et al 2007; MacDonald & Callery 2008; Parish et al 2012). According to a study by Sen and Yurtsever, half of the examined families reported family problems (Sen & Yurtsever 2007). Furthermore caring for an impaired child is linked to high costs (Sen & Yurtsever 2007; Gannoni & Shute 2010; Stabile & Allin 2012). According to Anderson and colleagues the consumption costs of caring for a disabled child range from 108\$ to 8742\$ annually (Stabile & Allin 2012). Stabile and Allin differentiate between direct economic costs (like out of pocket costs for medical treatment or travel costs) and indirect costs (for example by reduction of working hours or by quitting the job) which could negatively influence the life situation of affected families (Stabile & Allin 2012). Also a diminished income is inevitably linked with limitations on access to special treatments and services (Davis & Gavidia-Payne 2009; Resch et al 2012a; Anderson et al 2007; Viner Brown & Kim 2005) and can lead to prolonged

time on waiting lists for needed treatment (Resch et al 2012a). The high extent of required medical drugs could also increase financial strain (Murphy et al 2007). Furthermore, additional costs like home remodelling adapted to the child's needs or purchasing a car to carry the disabled child to medical experts or treatments can burden families (Ausserhofer et al 2009).

An issue discussed controversially in recent studies is the effect of reduced working hours on parents. Resch and colleagues show that a reduction in working hours could also lead to increased parental well-being (Resch et al 2012b). This may be linked to the result of Ausserhofer et al who found in their Austrian study that a reduction in working hours also is experienced as relieving by the care giving parents (Ausserhofer et al 2009).

Some of the articles clarify that mothers are more affected by a decreased quality of life than fathers in consequence of being the person reducing their working hours or quitting work in case of an illness of their child (Hexem et al 2011; Coffey 2006; Miller et al 2012; Blanchard et al 2006). This could be explained by the fact that mothers are then caregivers in most instances and therefore have to take most of the responsibilities of care for the disabled child. In contrast to the previously mentioned relationship between reduced working hours and an increased parental well-being, Hatzmann and colleagues describe a reduced mental health in unemployed mothers who care for a disabled child (2009). Reviewing the present studies show that mostly women are affected by reduction of or quitting work which can be explained by the fact that women are still care givers in most instances.

Furthermore families with a disabled child are more likely to be single parent families (Anderson et al 2007). Particularly these families have to cope with financial burdens (Anderson et al 2007; Parish 2012).

However, to which extent parents have to reduce working hours or even quit their jobs depends on the health condition of their child and how strong it is limited in its motor activity and physical constitution (Loprest & Davidoff 2004; Okumura et al 2009; Viner Brown & Kim 2005).

2.2.3 Costs due to housing situation

Another factor which is linked to financial costs is the housing situation. Having a disabled child sometimes requires changes or special facilities in housing environment, especially if the child has motor functioning restrictions (Bromley et al 2004; MacDonald & Callery 2008). In a study of Bromley et al 40% of the parents stated their homes were not adequate for looking after a disabled child, while the reason stated most is insufficient space (Bromley et al 2004).

2.3 Emotional burdens and support

In this chapter all disability related factors which are linked to the emotional well-being are summarized. As main categories overall support, mental and physical well-being, fear of/ experienced stigmatisation and a lack of time were identified and will be further described below.

2.3.1 Rating of overall support

Most available studies highlight the importance of lacking emotional support as an important factor which negatively influences parental well-being (Hatzmann et al 2011; Warfield et al 1999; Sen & Yutsever 2007; Donovan et al 2005; Gannoni & Shute 2009; Coffey 2006; Davis & Gavidia-Payne 2009; Resch et al 2012a; Resch et al 2012b). Two articles specify this aspect by describing that the majority of affected parents experiences loneliness (Ray 2002; Sen & Yurtsever 2007). This fact is strongly linked to the risk of social isolation which was furthermore found to be a parental burden (Gannoni & Shute 2009; Goldbeck 2006; Donovan et al 2005; Ray 2006; Resch et al 2012a). Particularly mothers wish to have someone to share their thoughts and sorrows with (Ray 2006). As possible reason for an emotional withdrawal of relatives and friends, Coffey identifies the fears and kind of discomfort of the social environment in offering help with caring for the disabled child (Coffey 2006). Donovan and colleagues point out, that family members communicate to offer support, while simultaneously sending out signals which suggest to the parents that actually they are not willing to help (Donovan et al 2005).

In a nutshell, Dellve et al describe that 60% of the affected mothers and 70% of the fathers rate the overall support they receive as “fairly good” or “good” for coping with their situation (Dellve et al 2006), while Sen and Yurtsever add that 71.8% of the parents receive emotional support from which 56.8% receive it from a family member and 9.5% from a specialist (Sen & Yurtsever 2007). Additionally, Poston and colleagues show that emotional well-being correlates with a good parent expert relationship. Parents desire to be listened to by health care professionals. Furthermore they want to be respected and understood (Poston et al 2003). However 43.6% experience the current support situation as inappropriate (Sen & Yurtsever 2007). Contrary to this statement, in the study of Blanchard et al the majority of the participating parents state that their support system which contains of family, friends and health care professionals, as sufficient (Blanchard et al 2006). Particularly the support of the partner seems to have a strong positive influence on parental well-being (Warfield et al 1999; Ray 2006). Fathers declare to have higher support by their partners (Dellve et al 2005). Sen & Yurtsever found out in their Turkish study that mothers often experience an assignment of guilt for the disability of their children by their partner and his family (Sen & Yurtsever 2007). However, this issue has not been mentioned in other studies. Maybe other researchers did not ask questions focussing on this aspect.

2.3.2 Mental and physical well-being

The majority of articles mention stress as a factor which negatively influences the parental well-being (Paster et al 2009; Lawoko & Soares 2003; Davis & Gavidia-Payne 2009; Crowe & Florez 2006; Resch et al 2012a; Benjak et al 2009; Ausserhofer 2009; Murphy et al 2007; Sloper & Beresford 2006; Hunter 2002), while only one article does not associate a relationship between caring for a disabled child and a decreased parental well-being (Boyras et al 2011). As factors which could negatively influence the parental stress level, Sloper and Beresford identify the challenging behaviour of the affected child, the poor, financial situation of the family, a lack of formal and informal support, and parents' adequate coping strategies (Sloper & Beresford 2006).

The level of stress experienced by parents depends on the severity of the disability and the care demands (Miodrag & Hodapp 2010). Generally, they seem to have a

worse overall perception of their health status and their quality of life than parents of healthy children (Mugno et al 2007). Mothers generally seem to experience higher levels of stress (Dellve et al 2005). This may be due to the fact that they are the caregivers in most of the cases. Bourke Taylor et al assume that mothers are the primary care givers in 95% of the families and therefore have to carry a higher burden of responsibility for the child's needs and concerns (Bourke Taylor et al 2012). Furthermore, Bromley and colleagues show that an increased level of distress appears together with a reported lack of support in caring for a disabled child (Bromley et al 2004). Parental strain is expressed by a variety of emotions and symptoms like depressive episodes (Hatzmann et al 2011; Coffey 2006; Lawoko & Soares 2003; Hexem et al 2003; Davis & Gavidia-Payne 2009; Resch et al 2012a; MacDonald & Callery 2008), fears (Ausserhofer et al 2009; Paster et al 2009; Sen & Yurtsever 2007; Ray 2006; Hexem et al 2011), anger (Paster et al 2009; Sen & Yurtever 2007; Poston et al 2003; Ray 2006) or anxiety (Paster et al 2009 ; Sen & Yurtsever 2007; Ray 2006; Hexem et al 2011; Poston et al 2003). Benjak and colleagues found out that 41% of the examined parents who have to care for a disabled child are suffering from at least one chronic illness compared to 30% of the parents with non-disabled children (Benjak et al 2009), while Thabet et al found out that 68% of the affected mothers suffer from anxiety and 52% from depression (Thabet et al 2013). Negative emotions like worries and frustration were oftentimes mentioned in connection with the behaviour of health care professionals towards the affected parents (Ray 2006). Additionally, previously mentioned negative emotions can lead to sleep disturbances in some cases (Hatzmann et al 2011; Brown et al; Crowe & Florez 2006; MacDonald & Callery 2008; Murphy et al 2007). Beyond that, MacDonald and Callery describe that some parents experience feelings like depression while recognizing that they will never realize their dreams (MacDonald & Callery 2008) because they will be mainly responsible for the care of their child lifelong.

2.3.3 Fear of or experienced stigmatisation

One article describes the fear of or the experienced stigmatisation as a circumstance which negatively influences parental well-being (Green 2003; Sen & Yurtsever 27). Green describes that parents feel ashamed and anxious.

Furthermore, Green as well as Sen & Yurtsever mentioned that some of the mothers were blamed for the disability (Green 2003; Sen & Yurtsever 2007) while Green specifies the reason of reproach as the refrain from abortion (Green 2003).

2.3.4 Lack of time

Another important point mentioned is the lack of time. Parents only have limited time for handling the enormous extend of daily care activities (Crowe & Florez 2006; Anderson et al 2007; Green 2003; Murphy et al 2007). A study by Dupont from 1980 examines the care requirements on the basis of the required time for care Dupont 1980). This study showed that parents on average spent 7,11h a day for the care of their disabled child. A newer study by Kulka in 2006 clarifies the care requirements of parents caring for multiple handicapped children; table 1 shows the average time requirements (Kulka 2006):

Field of activity	Time consumption in hours/week on average
Total time of care	61
Pure care time	3,11
Nutrition (part of basic care)	9,36
Hygiene (part of basic care)	6,37
Mobility (e.g. carrying, dressing) (part of basic care)	8,5
Curative care (e.g. medication)	2,16
Support and recreational activities	22,14
Home economics area	7,52

Table 1: Time consumption of activities

Crowe and Florez compared the time requirements of parents of disabled children with requirements of parents with healthy children without fractionizing the child care tasks into small parts (nutrition, hygiene, mobility, curative care) like Kulka does in her study. They focus on the aspects of recreation, child care, homemaking, personal care, socialisation, employment, education and rest/sleep. In this connection they came to the result that parents of disabled children spend on average 32.1 hours per week with child care activities, while parents of healthy children spent 19.0 hours per week on average (Crowe & Florez 2006). Anderson and colleagues report time costs for care giving ranging from four hours up to 84 hours a week, depending on the severity of the disability (Anderson et al 2007),

while Green looks at the time consumption of medical treatment (Green 2003) which is pandered by the fact that patient centred care is mostly separated and not bunched in one specialized centre (Ausserhofer et al 2009). Limited leisure time (Hatzmann et al 2011; Ray 2006; Green 2003) and restricted travel opportunities (Viner Brown et al 2005; Hatzmann et al 2011) were mentioned by parents as factors which could reduce their well-being, and also the lack of time for mental reflection and recreation (Poston et al 2003; Goldbeck 2006; Donovan et al 2005; Murphy et al 2007). In their study of 2006, Crowe and Florez found out that passive recreation like arts, browsing the internet or simply watching TV only takes 15.9 hours per week for parents with a disabled child in comparison to 21.4 hours per week in families of healthy children. The differences in active recreation like exercising seems to be less visible: while parents of disabled children spend on average 2.6 hours weekly, parents of healthy children spent 2.8 hours thus nearly the same (Crowe & Florez 2006). Crowe and Florez found out, that in the area of personal hygiene parents with a disabled child spent on average 9.6 hours per week while in families with healthy children parents spend about 12.7 hours per week for these activities (Crowe & Florez 2006). Spontaneous activities are impossible; all joint ventures have to be planned in advance (Ausserhofer et al 2009). Above all, there is a shortage of special local leisure facilities where families can spend their time as a family together with the affected child while the use of common leisure facilities may lead to hostile attitudes of staff and “healthy” families (Sloper & Beresford 2006).

However, Goldbeck found out that parents of disabled children albeit they have to face a lot of challenges, are significantly more satisfied with their family lives than families with healthy children (Goldbeck 2006). Furthermore, affected parents tend to rate their own health with lowest priority, while the well-being of the affected child and the family rank highest (Murphy et al 2007).

Two articles mention parental worries about the child’s future as something which could negatively influence the well-being (Green 2003; Ausserhofer et al 2009).

2.4 Formal support

In this chapter, all disability related factors which are linked to formal support are summarized. As main categories scarcities of support systems, criticism of health care professional behaviour, problems of accessibility of respite services and problems of mobility have been identified and will be further described below.

2.4.1 Scarcities of different support systems

Findings regarding the importance of formal support by health care professionals for parental well-being are diverse. Davis and Gavidia-Payne describe professional support as one of the strongest predictors for quality of life in families with a disabled child (Davis & Gavidia-Payne 2009). McManus and colleagues identify a link between caregiver burden and difficulties in navigating the health system and accessing formal support (McManus et al 2011).

Some articles highlight different support systems, which were described by parents as insufficient and in need for improvement. In this context support in home care and child care is mentioned frequently (Sen & Yurtsever 2007, Blanchard et al 2006; Resch et al 2012b). Additionally, the need of psychological support and counselling has been described in two articles (Sen & Yurtsever 2007; Donovan et al 2005). Other articles depict difficulties in accessing special services and treatments and furthermore problems in application of benefits by insurances or offices (Poston et al 2005; Ray 2006; Lutenbacher et al 2005). In this context the cooperation between health and social services and the educational system has been described as problematic (Ray 2006). Additionally, it seems to be a problem that many parents are not aware of resources and services which are available (Molinari & Freeborn 2006). To sum up, for many affected families denied services, waiting lists and delays of approvals lead to large out of pocket expenditures which additionally burden the families (Lutenbacher et al 2005).

The range of declarative statements in regard to dissatisfaction with formal support is wide: long waiting lists for special treatments (Steel et al 2011), insufficient or scarce supply of therapies and services (Steel et al 2011; Donovan et al 2005; Coffey 2006; Lutenbacher et al 2005) or available services, which are not adjusted to the needs of the families (Steel et al 2011; Donovan et al 2005; Coffey 2006; Baillargeon et al 2011). Contrariwise, 40% of the affected parents included in a

study by Donovan and colleagues report that needed services already exist, however they do not make use of it (Donovan et al 2005). As possible reason for non-utilisation of these services Lutenbacher and colleagues identify restricted availability or over complication due to bureaucratic processes (Lutenbacher et al 2005). Otherwise, Ausserhofer and colleagues mention as reason for withdrawal from support services that some parents feel supported by these services, but lack confidence in health care professionals (Ausserhofer et al 2009), while Molinari and Freeborn remark that parents in general prefer informal support (Molinari & Freeborn 2006). On the other hand, parents consider formal support as a basic right, while informal support by family and friends is sometimes considered as “the last resource” (Donovan et al 2005).

Parents describe different areas in which they want additional support. Donovan et al name “help in administrative and financial concerns and in unclear regulations and policies” (Donovan et al 2005), while Ray mentions “support to look through institutional structures and strategies” (Ray 2006)

To be confronted with all these challenges, burdens parents additionally and increases their work load. Ray calls this phenomenon “working the system”. He assumes that about 50% of the time parents need to care for their child is consumed by this phenomenon (Ray 2006). In turn this would mean a reduction of possible challenges in regard of formal support could facilitate the parental management and therefore decisively relieve their situation.

2.4.2 Criticism on health care professionals behaviour

Some of the affected parents criticise the way health care professionals treat them. They experience little respect and acceptance (Donovan et al 2005; Gannoni & Shute 2009; Ray 2006; Resch et al 2012a; Coffey 2006; Lindblad et al 2005; Lutterbach et al 2005; Hunter 2002). Furthermore, some health experts tend to use technical terms and an unclear style of communication which complicates appropriate support (Donovan et al 2005; Lindblad 2005).

Coffey explains that parents indeed appreciate the expertise and knowledge of experts; however they want their own competences regarding the ill child and its treatment to be valued (Coffey 2006; Lindblad 2005; Hunter 2002) by the professionals and their concerns and demurs to be taken seriously (Lindblad

2005), because they know their child and its requirements best. Being ignored as a helpful supporter for the own child can lead to frustration and anger in the affected parents (Murphy et al 2006).

Additionally it becomes clear that formal support both in hospitals and by registered doctors, mainly focuses on the concerns of the affected child without considering the family environment. The needs of parents or siblings are oftentimes ignored (Donovan et al 2005). Two of the articles emphasize that an improved formal support could allow affected families to spend more time together (Poston et al 2005; Donovan et al 2005). Referring to that Steel and colleagues describe the lack of practical help and support offers for families. Especially support on weekends and on vacation times seems to be a problem and to complicate commonly family activities (Steel et al 2011).

2.4.3 Problems with availability and use of short-term services

Other problems which have been frequently discussed in the reviewed articles are difficulties with availability and use of short-term services (Sloper & Beresford 2006; MacDonald & Callery 2008; Baillargeon et al 2011; Lutenbacher et al 2005). Short-term services are offering short-term, temporary relief for those who have to care for relatives who might otherwise require permanent placement in a care facility outside their home (National Respite Network 2013). Lutenbacher more precisely describes the lack of respite care support on the basis of the following factors: a lack of facilities where disabled children could interact and communicate with each other as well as a lack of trained and available staff which could provide this service in homes (Lutenbacher et al 2005). MacDonald addresses the issue of fragmentation of respite services. This makes it difficult for parents to seek adequate support on the one hand; on the other hand they don't want to repeat their story several times (MacDonald & Callery 2008).

2.4.4 Problem of accessibility of services and support

Skinner and Sklifkin mention in their article another important issue, which should be addressed at this point: the accessibility aspect. Therefore, families in rural areas have a greater burden of care than families living in urban or suburban areas. This is due to the fact, that specialists and medical experts are hard to

reach because most services are not provided in rural areas (Skinner & Sklifkin 2007). Added to the accessibility problem, families in rural areas seem to have less money to pay for special treatment. This is because people with less income more often move to rural areas because of the lower hiring charges (Skinner & Sklifkin 2007). While rural and urban families both have likewise levels of unmet care needs, rural families experience increased system level problems in accessing care due to far distances and no adequate public transport, they have more income related problems and spend more time in finding and providing care for their children (Skinner & Sklifkin 2007; Aussenhofer et al 2009). Due to the financial aspect having a car can be seen as a matter of course to solve the problem of accessibility.

2.5 Familiar strains

In this chapter, all disability-related factors linked to familiar strains are summarized. As main categories restrictions in social activities, influence on the parental partnership and the fear of neglecting siblings have been identified and will be further described below.

2.5.1 Restrictions in social activities

Caring for a disabled child determines the daily routine of affected parents. The majority of articles clarify, that isolation and a restricted social life are observed problems which have a significantly negative influence on parental well-being (Paster et al 2009; Hatzmann et al 2011; Sen & Yurtsever 2007; Lawoko & Soares 2003; Stabile & Allin 2012, Green 2003; Aussenhofer 2009; Baillargeon et al 2011; MacDonald & Callery 2008; McConnell & Llewellyn 2006; Mugno et al 2007). The reviewed articles make clear, that having a child with a disability could modify already existing friendships: on the one hand some friends tend to withdraw from the affected families; on the other hand some enhance their support and care (Ray 2006; Poston et al 2005). Some friends simply feel uncomfortable in supporting parents with the care of the disabled child (MacDonald & Callery 2008).

Green mentions in her article that some mothers have the feeling that family and friends do not understand their situation and their changing priorities (Green 2003). This can additionally complicate social interactions.

2.5.2 Disabilities influence on the parental partnership

Furthermore the disability of the child can have an impact on the parental partnership in a negative or in a positive way. Statements on this are very diverse in the reviewed articles. Warfield et al as well as Resch describe break up and divorce rates which exceed the general population rates (Warfield et al 1999; Resch et al 2012a), while Ray claims that this predominant assumption of higher divorce rates cannot be proven. According to his study, the divorce rate in this special group does not exceed rates of the general population (Ray 2006). Beyond that he describes how differently parents experience the development of their partnership in such a situation: while some partnerships tend to break up because these parents cannot handle the new situation as a couple, some others converge (Ray 2006). Also two other articles indicate, that the shared responsibility in caring for a disabled child brings couples closer together again (Murphy et al 2007; Ausserhofer et al 2009). Only 10% of the affected couples Murphy studied ended up in divorce (Murphy et al 2007). However, Reichman and colleagues report that caring for a disabled child decreases the probability of staying together as a couple by 10 percentage points (Reichman et al 2008). As possible reasons for family conflicts, Miller identifies misunderstandings and missing communication among the family members in affected families (Miller et al 2012).

2.5.3 Fear of neglecting siblings

Another challenge which has been mentioned several times is the care for siblings. Parents fear to neglect the healthy siblings (Ray 2006; Murphy et al 2007; McDonald & Callery 2008), at once they worry about the disabled child's future (Ray 2006; Resch et al 2010; Lindblad et al 2005; Novak et al 2012; McDonald & Callery 2008; Murphy et al 2007). McDonald and Callery describe the time aspect which parents mention as a problem to attend to the siblings adequately (McDonald & Callery 2008).

2.6 Information and counselling

This chapter summarizes all disability related factors which are linked to information and counselling. As main categories insufficient education/information of medical staff, lack of information and lack of well-educated teachers have been identified and will be further described below.

2.6.1 Insufficient education/ information of medical staff

The analysis of the present articles showed that inappropriate or missing information about the child's disease, its diagnosis and possible progress burdens parents a lot (Sen & Yurtsever 2007; Gannoni & Shute 2009; Coffey 2006; Ray 2006; Davis & Gavidia-Payne 2009; Resch et al 2012a). Particularly with regard to diagnosis, Maciver et al highlight the importance of an early detection because professional help can be addressed fast which could positively influence the progress of the disease (Maciver et al 2011).

Furthermore, two of the articles add that an adequate education about the state of health of the child is an important influencing factor on parental well-being (Sen & Yurtsever 2007; Poston et al 2003). Dellve and colleagues describe perceived incompetence of medical staff to negatively influence the parental stress level (Dellve et al 2005). Furthermore six articles show that an abundance of information and knowledge from the professional side could negatively influence parental well-being, too (Gannoni & Shute 2009; Coffey 2006; Maciver et al 2009; Molinari & Freeborn 2006; Ausserhofer et al 2009; Lutenbacher et al 2005). Parents criticize that health care professionals oftentimes do not provide sufficient information about the child's condition which could lead to uncertainty and anxiety (Maciver et al 2009; Novak et al 2012; Lindblad et al 2005). According to a study by Thabet and colleagues, an impaired quality of life was found in 66% of the participating parents who stated that they were unsatisfied with the information they received by the medical staff (Thabet et al 2013). If this is the case, parents tend to weigh up independently, which kind of information they really use to be prepared for future care situations and which information they could get rid of (Coffey 2006).

2.6.2 Lack of adequate, easy assessable information

Blanchard and colleagues point out the demands of the affected parents: they wish to have free access to accurate information and correct, sufficient support and advice by health care professionals and furthermore they expect moderate professional competence (Blanchard et al 2006), while three other studies highlight the importance of transfer of sufficient information about legal rights and how to apply for special services (Lindblad et al 2005; Ausserhofer et al 2009; Lutenbacher et al 2005). Five other articles mention an improvement of allocation and search for information as well as respective support to find information about services and possible treatments as important aspects (Davis & Gavidia-Payne 2009; Resch 2012a; Ray 2006; Lutenbacher et al 2005; Hunter 2002). The deficit of knowledgeable experts and service providers also supports the use of the internet to find information about the disease, benefits and possible treatments and therapies. A study of Blackburn and Read shows, that 72% of the affected parents are browsing the internet to search disability specific information. However, they highlight the barriers which parents experience while using this search strategy: 85% of the parents find the search ineffective while 79% perceive some homepages as hard to find and difficult to handle (Blackburn & Read 2005). In addition, it is not self-evident that everyone has access to the internet (Blackburn & Read 2005).

Resch and colleagues as well as Hunter add that adequate access to information and resources is experienced by parents as relieving (Resch et al 2012a; Hunter 2002) and furthermore leads to a reduction in their stress level and by this to an increase in overall satisfaction (Resch et al 2012b). 75% of the mothers and 67% of the fathers report in a study by Dellve et al, that sufficient knowledge relating to the disability of their child is helpful to overcome the everyday challenges they have to face (Dellve et al 2005). However, the required disease specific knowledge not only concerns health care providers and medical staff, but also teachers and kindergarten teachers who work with disabled children. Therefore a lack of understanding of the child's condition has been mentioned as a problem (Novak et al 2012).

2.6.3 Lack of experienced, well-educated teachers

Especially the schooldays are a challenge for affected parents. Not only the previously mentioned lack of adequate education of teachers regarding the disability is a problem, but also worries about a sufficient integration and education of the child (Murphy et al 2007; MacDonald & Callery 2008; Anderson et al 2007; Bourke Taylor et al 2012). Lutenbacher mentions the additional resources which are needed to meet the needs of the affected child: additional staff, more time and supportive, motivated and well educated teachers (Lutenbacher et al 2005).

However, Ausserhofer et al furthermore describe the school enrolment as relief, because by the caretaking parent does not have to stay at home with the child for the whole day (Aussenhofer et al 2009).

All burdens and challenges which have been mentioned in chapter 3 are problems which parents of children with disabilities or chronic diseases *in general* have to cope with. This assignment tries to analyze to which extent the illustrated burdens are in accordance with the needs of parents caring for a child with Rett syndrome. Furthermore, disease specific burdens and needs should be specified and further described in particular.

3 Methods

In this chapter research questions as well as theoretical considerations relating to the choice and justification of the used research strategies will be stated. Furthermore, the process of the research will be illustrated.

3.1 Research questions

For exploring the situation of parents caring for a child with Rett syndrome, different research questions have been developed which should be addressed in this study. The leading question has been defined as following:

“What does it mean to be the care giver for a child with Rett Syndrome?”

As further research questions, which derive from this main one and supplement the main question, the following 3 questions were developed:

1. Which impact does the disability of the child have for the parental life situation?
2. Which areas of life are especially affected and how?
3. How could the situation/ well-being of affected parents be improved?

3.2 Research methods

3.2.1 Justification of using qualitative research methods

Qualitative research applies a person-centred and holistic perspective. It aims at understanding and appreciating human experiences from the perspective of affected persons, and at the development of theories or concepts which are constructed on the basis of these subjective experiences (Mayring 2002, p. 19). Therefore qualitative research methods can be used if there is little known about a specific phenomenon or problem (Morse & Field 1995).

As the literature review has shown, the situation of parents who are caregivers for a child with Rett syndrome is a relatively unexplored field of research. Furthermore, the way how parents' experience their situation and which possible problems and challenges they have to cope with is strongly subjective and therefore using a qualitative approach seems to be appropriate to acquire in depth knowledge about the parental situation. Furthermore, qualitative research allows more openness on participants' side and therefore may provide the researcher with a wider spectrum of possible answer categories than quantitative focussed research which is restricted to predefined categories. It furthermore allows interpretation of the research problem and therefore a detailed understanding of the findings (Creswell 2007, p. 39).

For exploring how parents experience the situation of taking care of a child with Rett syndrome the hermeneutic phenomenological approach has been chosen. This inquiry allows profound insight into how the parents experience their situation and strongly focuses on their feelings and personal perceptions (Creswell 2007, p. 59).

3.2.2 Philosophical Assumptions and Paradigm

Using a qualitative approach as inquiry for research includes reflecting on philosophical assumptions and the most appropriate paradigm in advance. This study acts on the assumption to reveal parents' perspective and on how they perceive their life and the society with its structures. It wants to describe how these parts are interlocked (Creswell 2007, p.15). The researcher wants to give parents a voice by giving them the chance, to freely narrate on own experiences and perceptions of their life situation. By this, the way of how society handles people with disabilities and their caregivers can be emblazed, possible marginalisation and stigmatisation of disability will be fathomed. The researcher used colloquial language to make the study understandable for readers. However, she minds to meet the standard of academic writing. The process of research is described as complete as possible by defining every process step and by using tables and examples. This procedure makes the whole process comprehensible for readers (Creswell 2007, p.31).

As paradigm which represents the researchers' beliefs best, the social constructivism was chosen for this study. This paradigm is often used in phenomenological studies. The characteristic of this worldview is that weight is given on how participants view the world and their own situation. The researcher starts with developing a scheme of meanings of a specific situation and interprets her findings in the end. Thereby she wants to make sense out of the participants' meanings about the world (Creswell 2007, p.20). By using the interpretative framework of disability theories, the study puts emphasis on how disabled individuals and their carer are embedded in the community and how society responds to them. It furthermore investigates to which extend their needs are adequately respected in their current situation (Creswell 2007, p.30).

3.2.3 Phenomenological Research

Phenomenological research in general aims to describe the meanings and significances for individuals and how they experience a specific phenomenon. It explains what affected individuals have in common while experiencing a specific phenomenon by reducing their individual experiences to the description of an overall essence. Phenomenology is strongly influenced by the epistemological

assumptions about the way how knowledge is gained and constructed: Phenomenology focuses on the perceptions of individuals, what and how they experience different situations and circumstances with the goal to describe accurately feelings, needs and processes of individuals (Creswell 2007, p.58).

Phenomenology is strongly influenced by the German philosopher Husserl who considers it as a strong philosophical method. He describes the approach as following: "Phenomenology acts considering clarifying, meaning defining and meaning distinguishing. It compares, connects, relates, separates the parts or separates moments" (Husserl 1986, p. 163). According to that, phenomenology can be seen as philosophy of consciousness, because it deals with the question of how things appear to the consciousness (Husserl 1986, p. 163).

Later, other philosophers like Heidegger or Sartre drew on the writings of Husserl and expanded and adjusted their notion of phenomenological research. Heidegger assumes that only phenomenological research of human experiences could fathom the sense of being (Watson 1996). Human phenomena do not behave like objects and therefore cannot be examined as such. They are expressed in moods, feelings and experiences. Phenomenology aims at understanding of a specific phenomenon and tries to capture experiences and intentions of persons in their living environment (Morse & Field 1995). However there is a multitude of different phenomenological approaches, all assume that phenomenology means the study of lived experience of individuals, that all these experiences are conscious and that the findings should not only be explained by the researcher but rather a description of a universal essence should be aspired (Creswell 2007 p. 59-60).

There are two different approaches of phenomenological research which are often used in health sciences and nursing sciences: the empirical, transcendental phenomenology according to Moustakas (1994) on the one hand, the hermeneutic phenomenology according to van Manen (1990) on the other hand. Moustakas has a strong focus on the description of the experiences of individuals.

According to his approach, researchers have to bracket out already existing experiences to capture a specific phenomenon or problem without being biased by personal beliefs or prejudices. This allows a fresh and uninfluenced view on the situation (Moustakas 1994 in: Creswell 2007, p. 60). This method is useful if the researcher targets to understand experiences from the angle of the researched person. It does not only focus on a consideration of a situation but rather on how

the affected person experienced the situation (Creswell 2007, p.60). Moustakas has predefined rules for the process of conducting a phenomenological study. As a first step the relevant phenomenon has to be identified. Then the data has to be collected from different individuals who have experienced this specific phenomenon. Following, the data is analysed by reducing the information to significant statements (horizontalization) first and summarized into themes (cluster of meanings). Afterwards the textural description (what the participants' experience) and the structural description (how they experience it) will be conducted by asking two leading questions. In the end a combination of both types of descriptions will lead to the development of an essence which provides an understanding of the common experiences of the individuals (Moustakas 1994 in: Creswell 2007, p.60).

The hermeneutic phenomenology according to van Manen (1990) combines the descriptive type of the transcendental phenomenology with the interpretative aspect of hermeneutics (van Manen 1990 in: Creswell 2007, p. 59). This approach reviews the meaning of the phenomenon in an interpretative way, which therefore exceeds the descriptive phenomenological approach. It aims to describe experiences of affected persons, to examine their meanings and thereby to identify the basic structure of the phenomenon. Meanings, which are hidden and not directly reveal to investigation or analysis should be interpreted by using this approach (Creswell 2007, p. 59). Using the phenomenological hermeneutic approach allows the researcher a relatively free course of action in data analysis because van Manen did not define a strict set of rules or methods for data analysis. However, he defined a set of six recommendations which should be followed while adopting the hermeneutic phenomenological inquiry:

1. The researcher should study a phenomenon of high interest.
2. The researcher should think about important themes that constitute the nature of this lived experience.
3. The researcher should write a description of the phenomenon.
4. The researcher should maintain a strong relation to the topic of inquiry.
5. The researcher should balance the parts of the writing as a whole.
6. The researcher should consider that is not only a description but it is also seen as an interpretative process in which the researcher makes an

interpretation of the meaning of the lived experience (van Manen 1990 in: Creswell 2007, p. 59).

For this assignment, the use of the open analysis according to van Manen seems to be most appropriate because constructing the analysis on two leading questions (what and how parents experience the phenomenon of caring for a child with Rett syndrome) like Moustakas does in his approach is not constructive for the own approach. Aim of the study is not the psychotherapy of affected parents but rather an in depth view into their situation and disability specific burdens and needs they have to cope with.

The researcher herself never worked or lived with a person who has a disability and does not have children. As source for her first orientation in this field the literature review was conducted in advance.

Given that van Manen does not offer a set of rules for the process of analysis, the framework of the summarizing content analysis according to Mayring will be used to analyse the results (Mayring 2003, see chapter 4.5). The researcher will interpret the content of the interviews as a further step (van Manen 1990 in Creswell 2007, p. 59).

3.2.4 Problem Based Interviews

The problem based interview technique was chosen as instrument for data collection. By using this form of interview the interviewees could illustrate, justify and interpret their conceptions and definitions of reality. Thereby, they become experts in semantic contents (Mayring 2002, p. 69). This kind of interviews put the principle of narration in the foreground; however the course of the conversation is in contrast to the narrative interview not boundlessly free (Lamnek 2010, p. 364). The interviews were conducted in a semi structured way which allows the researcher to gain more in depth information rather than by only using a predefined questionnaire. Therefore, the researcher used an interview guideline as a leitmotif. However, the interviewer has the opportunity to deviate from this guideline, to change the order of its questions or furthermore to add additional questions. The guideline solely serves as an assistance tool to remind the researcher of relevant aspects throughout the course of the interview. If

necessary, the researcher can revert to it, otherwise the interviewees are summoned to answer freely without restrictions by the researcher and will be animated to narrate and to explain what they consider to be important for analysing the object of research (Lamnek 2010, p. 352). By using this procedure it should be assured that all topics of interest were covered without hindering the story line by predefined questions, so the aspects of the guideline were introduced in a wording that best fit the language of the interviewees, following their priorities and allows a free narration. The researcher has to consider that the interviewees can express their attitudes and perceptions of the social reality. Therefore, he or she takes on the role of an interested but reluctant listener who adapts to the interviewees' mode of telling (Lamnek 2010, p. 338). To keep the narration continuity the interviewer can repeat the last statements of the interviewee or paraphrase it (Lamnek 2010, p.365).

The interview guideline is structured as following:

As an introduction, the researcher described her situation, her previous fields of work and why she decided to do her study in this area. She highlighted her interest for the topic. By this, she created mutual trust and furthermore it allowed a relaxed entry into a conversation. Additionally, she asked the interviewee about his/her consent of recording the interview and using the information. The three relatively general questions were asked as a next step:

“How do you experience the daily life with your child? Please tell me what a typical day looks like.”

(„Wie empfinden Sie den Alltag/ das tägliche Leben mit ihrem Kind? Erzählen Sie doch mal, wie ein typischer Tag bei Ihnen aussieht.“)

“To what extent do you perceive changes in your life due to the disability of your child?”

(„In wieweit hat sich durch Ihr Kind und die Behinderung Ihr eigenes Leben verändert?“)

“Are there everyday situations with your child which you experience as particularly burdening? And if so: Why do you feel like this?”

(„Gibt es Situationen im Alltag, die Sie als besonders belastend oder problematisch empfinden? Wenn ja: Warum?“)

These questions are good icebreakers and allow the interviewees to freely narrate on how they experience their daily life with a child with Rett syndrome. These questions do not zoom in on specific predefined categories and therefore allows a wider variety of possible answers.

The other questions were more focussed on specific topics, which were identified by gathering the literature review. They briefly cover the main categories which were generated throughout the review:

- Financial situation
- External support
- Own health status
- Social life, family and partnership

The questions were adjusted to the interview situation; however the guideline comprises suggestions in each category to alleviate the situation and to remember the researcher which subcategories could be additionally included.

Concluding, the interviewees were asked about additional information they considered to be important and included into the study. Furthermore, they were asked if there is something they would like to change to enhance the parental situation and if so: how they would do it.

To get an overview about the different interviewees in the end, some demographics were asked, too:

- Age of the affected child
- Age and number of siblings
- Place of residence

The researcher offered the interviewees to send them the results after completion and assured them of anonymity and data security.

The complete interview guideline is attached as appendix 1.

3.2.5 Pre-Test

A pre-test on the manageability of the guideline was conducted with the group leader of the Rett parental initiative of Lower-Saxony which was conducted in the framework of a previous study, namely “Exploration of Quality of Life of chronically ill or disabled children in Hamburg” which will be further described in chapter 4.2.6. However, the previously used interview guideline was not geared on the phenomenological approach but rather on results of the preliminary literature review, it gave a first overview about important areas which had to be covered in the new study. The conduction of this pre-test allowed an adaptation and modification of questions and questioning techniques and gave the researcher a first insight into the new interviewing situation.

3.2.6 The sample

The selection of participants was not based on criteria of representativeness, but in fact on the selection of typical cases (Lamnek 2010, p. 193). Therefore two different groups of interviewees were recruited to get a deeper understanding of the situation of parents caring for a child with Rett syndrome from different points of view:

1. **Self-help group leaders of parental initiatives** because they have an overview about the situation of their group members in general
2. **Parents who are care givers for a child with the Rett syndrome** because they can give an insight in their own experience with a disabled child.

The first contact was established thorough a research project which the researcher conducted in her research internship¹ during her Master Studies at HAW Hamburg at the Department for Medical Sociology, Social Medicine and Health Economics at the University Hospital Hamburg-Eppendorf² in collaboration with the

¹ Advisor: Prof. Dr. C. Färber

² Advisor: Dr. phil., Dipl.-Psych. C. Kofahl

Kindernetzwerk e.V. That project was similar to the composition of this study but covered the situation of parents of chronically ill and disabled children in general. During this project, seven interviews with group leaders of parental self-help groups in and around Hamburg were conducted. One of these groups was the regional branch Hamburg/Schleswig Holstein of the self-help group of parents with a child with Rett syndrome. The researcher kept in touch with the group leader who facilitated the contact to the group members organized in the self-help group and offered a list of possible participants who evinced their interest in taking part in the study.

There are eight other regional branches which all were contacted via email, informed about the planned study and invited for participation. Covering affected parents nationwide seems to be adequate to consider possible regional differences.

The contact data of the corresponding group leaders was found on the homepage of the "Elternhilfe für Kinder mit dem Rett Syndrom"³. Furthermore, a request was sent via email to the director of the committee office with the demand for distributing it via email to the members.

Following group leaders agreed to give an interview:

- Regional branch Lower Saxony/Bremen
- Regional branch Mosel Saar Pfalz
- Regional branch Bavaria

While conducting the interviews it emerged that some of the interviewees are currently in the steering committee of the regional branches, too.

The group leaders act as gatekeepers (Flick 2002, p. 92) who made contact to affected parents who are organized within the parental initiatives. In addition to the list of possible participants which was offered by the group leader of Schleswig-Holstein/Hamburg in advance, parents of other regional branches called the researcher personally or sent her an email to communicate their interest in participating in the study.

³ www.rett.de

In total 21 group members volunteered to participate. The selection was done according to the order in which the possible participants replied. A total of 15 interviews were conducted until saturation was reached (Lamnek 2010, p. 189). This means that there no new issues were raised. So parents out of eight federal states could be included. The overall length of the interviews ranged between ½ hour and 1½ hour.

As inclusion criteria for a possible participation of the parents the following criteria where defined in advance:

1. at least one child is affected by the Rett syndrome
2. the parents have cared for their affected child at home or still do
3. The parents are organized in a self-help group
4. The interviewee gave informed consent in advance
5. The interviewee was German speaking

The following table gives an overview about the participants:

ID	State of Residence	Age of Affected Child	Age of Sibling	Care Provider
I01*	Saarland	17	-	School; home-care
I02*	Lower-Saxony	25	28	Foster group (full-time)
I03*	Saarland	23	-	Foster group; home-care
I04	Schleswig-Holstein	16	19	School; home-care
I05	Schleswig-Holstein	19	-	Sheltered workshop (full-time)
I06	Schleswig-Holstein	17	19	School for mentally and physically handicapped children; home-care
I07	Saxony	11	1 ½, 5	All-day school; home-care
I08	Bavaria	10	12	School; home-care
I09	Schleswig-Holstein	22	24; 15; 16	Employment-promotion-group; home-care
I10	Schleswig-Holstein	6	10	Integrative Kindergarten; home-care
I11	North Rhine-Westphalia	19	22	School; home-care
I12	Bavaria	15	8	School for multiple disabled children; home-care
I13	Brandenburg	17	33; 26	Special school; home-care
I14	Schleswig-Holstein	18	21	Foster group; full-time care facility
I15	Mecklenburg-West Pomerania	10	-	School with focus on mental development; home-care

Table 2: Demographics of participants

3.2.7 Conduction of interviews

To get the most authentic information by the interviewees, a preferably naturalistic environment should be built (Lamnek 2010, p. 392). Therefore, the ambition of the researcher originally was to conduct all interviews in the interviewees' homes. However, the interviews were conducted via telephone (Skype) in the end due to the fact that within the framework of this master thesis there were no funds to cover travel costs. Furthermore there was no car available to reach the interviewees' hometowns in reasonable time and most lived in rural and remote areas. Therefore all participating parents and most group leaders were interviewed via telephone. Due to the fact that telephone interviews do not allow direct personal contact between the interviewees and the researcher, it was of particular importance to establish mutual trust. Therefore the interviewer was using a so called "soft communication style" which means that the researcher tried to create mutual trust by demonstrating her sympathy for the interviewee and the situation (Lamnek 2010, p. 343). Thereby she built a relaxed and open atmosphere to get as much information as possible without influencing the interviewee. Furthermore, the style of speech of the interviewee was adapted to enhance confidence (Lamnek 2010, p. 348).

The interview with the self-help group leader of Lower Saxony/Bremen was the first one which was conducted and furthermore the only face-to-face interview. In this case the researcher strived towards conducting the interview in a calm and relaxed environment, so it took place in a quite café in Hamburg.

The interviews were conducted over a period of two months (3rd May 2013 until 2nd July 2013). After achieving informed consent, all interviews were recorded on audiotape. Afterwards, an analogous transcription of these records was done which will be further described in cap 4.5.1.

3.3 Validation of results

To validate the results two actions were taken. The first step was **communicative validation**. At this juncture the imposed data and results were submitted to the respective participant with the aim of assessing it with respect to its validity (Lamnek 2010, p. 155). This process was conducted for all participants and thereby allows alterations of findings depending on the perspective of the

participant. The communicative validation took place after the particular interview was transcribed and categorized.

As a second step equalization with complementary methods was conducted. By this process of **triangulation** the results were compared with the already existing results of the literature review as well as with information material of the different Rett parental initiatives in terms of similarities, differences or specifics (Lamnek 2010, p. 147). This cross verification tries to balance the weaknesses of each approach or data source and therefore can reduce systematic errors (Lamnek 2010, p. 158).

3.4 Ethical considerations

By conducting qualitative studies some ethical implications have to be considered. The following considerations are important with regard to this study, so it is outlined how the researcher targeted these aspects.

Reciprocity (Hatch 2002): Every research project should report on how participants will gain from the corresponding study. Participants invest effort and time in participation and therefore conducting such a study should be beneficial for them somehow.

This study is conducted to raise awareness for the situation of parents caring for children with Rett-syndrome and therefore pursues the goal to improve their situation. The purpose was further described in chapter 1.2.

Personal data security (Hatch 2002): The researcher has to reveal to the participants what happens with their personal data. Therefore she conferred with them in advance to discuss the use and publication of the results. Anonymity and confidentiality is protected by using identification codes (I01 to I15) instead of names.

Respect privacy rights and right of withdraw (Hatch 2002): The researcher complies with the requests of the participants with respect to date and place of the interview and asks questions in an empathic way without violating privacy rights. Furthermore, every participant had the right to withdraw from the study at any time without stating reasons. This was communicated to the participants prior to the interviews.

Informed consent (Hatch 2002): To assure the permission to use the data which had been gained by the interviews and informed consent was obtained by the participants prior to data analysis. This informed consent was not in paper form, but permission was recorded on audiotape.

3.5 Data analysis procedures

3.5.1 Process of Transcription

As first step of analysis the recorded interviews have to be transcribed. This means to transfer spoken language into writing (Mayring 2002, p. 89). As type for transcription literal transcription was chosen but with confinements (Mayring 2002, p. 89) because the main interest of the researcher is the analysis of the content rather than the analysis of the text form. Thereby speech pauses, verbiages, “ohs”, “ahs” and other redundant or non-content modifying statements, grammatical mistakes or sentence structure were deleted or corrected. Furthermore, dialects were translated into standard German and the style was evened (Mayring 2002, p. 91). For a better conformability and transparency of the analysis, the lines were numbered. Within data analysis, corresponding statements of the interviewees were represented under specification of interview-ID and analogous line-number.

3.5.2 Summarizing Content Analysis

The analysis was conducted according to the summarizing content analysis of Mayring (2003, p.61). The advantage of this framework is that it can be considered as methodologically controlled and allows a stepwise analysis of the material by resolving it into small units which can be worked on consecutively (Mayring 2002, p. 61). The focus of the summarizing content analysis is on developing a category system. Thereby, important aspects which should be filtered out of the present material can be defined. This type of analysis is suitable for systematically handling material, especially for a large quantity of text (Mayring 2002, p. 61) like in this study. Mayring describes the aim of the summarizing content analysis as following: “...to reduce the material in a way in which the essential content is preserved, to generate a manageable corpus by abstraction which however

represents a copy of the raw material” (Mayring 2002, p.58). The basic idea of the summarizing content analysis is to unify the information of the material by reduction (which includes paraphrasing, generalisation and reduction, before shortening and categorizing it (Mayring 2003, p. 59).

As a first step of the summarization the coding units and context units must be defined. Coding units specify the smallest textual component which can be assigned to one of the categories which will be constructed. In contrast context units specify the biggest textual components. Coding units comprise every statement of the participant regarding the situation of interest while context units comprise all places of findings within the interview (Mayring 2003, p.52).

The direction of analysis is defined as a reduction of the basic raw material into a predefined level of abstraction: abstract conclusions were gained by omission, generalisation, construction, integration, selection and bundling. By these conclusions the raw material is paraphrased. It can be reduced stepwise according to Mayring`s z-rules and thus the level of abstraction can be increased (Mayring 2003, p. 62).

Z1: Paraphrasing

- Z1.1 Deletion of unsubstantial textual components (e.g. embellishing, repeating explanations)
- Z1.2 Translation of important text passages into a consistent level of language
- Z1.3. Transforming into grammatically shortform

Z2: Generalisation to the level of abstraction

- Z2.1 Generalising the item of paraphrase to the defined level of abstraction so that the old items are implicated to the new formulated ones.
- Z2.2 Generalising of statements in the same way
- Z2.3 Leaving the paraphrases which are above the aspired level of abstraction
- Z2.4 Use theoretical presumptions in cases of doubt

Z3: First reduction

- Z3.1 Deleting of synonymous paraphrases within an analysis unity
- Z3.2 Deleting paraphrases which are not considered as content full on the new level of abstraction

Z3.3 Adopt paraphrases which still are considered as content full (selection)

Z3.4 Use theoretical presumptions in cases of doubt

Z4: **Second reduction**

Z4.1 Summarizing paraphrases with same or similar item and similar statement to one paraphrase (bundling)

Z4.2 Summarizing paraphrases with diverse statements to one item

Z4.3 Summarizing paraphrases with the same or similar item and different statements to one paraphrase (construction/integration)

Z4.3 Use theoretical presumptions in cases of doubt (Mayring 2003, p. 62)

According to Mayring, the analysis of the text was done on the basis of the z-rules (Mayring 2003, p. 62). However the researcher simplifies this process by using only one step of reduction.

In this study, the smallest text units which can be assigned to a category are defined as sentences (coding unit) while the biggest text units which can be assigned are defined as passages (context unit). The researcher first worked through the material line by line and highlighted all units which are of particular interest for answering the research questions. As recommended by Mayring, these units were paraphrased by reducing them to its content without distortion. Thereby a common level of language was created. As a next step, these paraphrases were generalized to the same level of abstraction. By this, many paraphrases with same content arise. Meaningless paraphrases were crossed out and similar paraphrases were bundled. Thereby new statements were constructed. By this process of reduction the material for the inductive category system was developed. The categories derive directly out of the present material and represent the generalized statements of the raw material. Concluding, the units which were defined in the beginning were adjusted to the developed category system. By this, 32 sub-categories were identified (see table 3). As a next step all these sub-categories were reviewed and summarized into seven main categories. In the description of the results, every sub-category is presented by a representative statement under specification of interview- and line number to make the process more reproducible. The categorisation was conducted by using MAXQDA qualitative data analysis program.

Main categories	No. of Sub-category	Sub-categories
C1: Everyday-life	Category 1	Challenge of care
	Category 2	Challenge of communication
	Category 3	Challenge of mobility
	Category 4	Accessibility of services
	Category 5	Structural circumstances
	Category 6	Potential relief
C2: Formal support and strains	Category 7	Late diagnostic
	Category 8	Disease-specific knowledge
	Category 9	Health professionals' behaviour
	Category 10	Short-term care and fulltime-care facilities
	Category 11	Nursing staff
	Category 12	Benefits of health insurances
	Category 13	Allocation of care levels
	Category 14	School situation
C3: Financial barriers	Category 15	Labour situation
	Category 16	Care allowance of parental nursing-care
	Category 17	Additional costs
C4: Personal health	Category 18	Time for recreation
	Category 19	Psychological situation
	Category 20	Physical situation
C5: Social support and strains	Category 21	Leisure/social time
	Category 22	Societal acceptance
	Category 23	Guilt and reproaches
	Category 24	Familial acceptance of the disability
	Category 25	Impact on partnerships
	Category 26	Impact on friendships
	Category 27	Impact on siblings
C6: Coping-strategies	Category 28	Open-minded-approach
	Category 29	Avoidance of confrontation
	Category 30	Level of awareness
C7: Prospects	Category 31	Release
	Category 32	Future thoughts

Table 3: Categories and sub-categories

4 Description of Results

4.1 Coping with everyday-life

This category includes all statements elaborating on the care of a child with Rett syndrome in everyday-life. Care, mobility and communication are identified as challenges, but also access to medical care and structural problems burden everyday-life. Supporting networks provide relief.

4.1.1 Care as a challenge

The majority of parents see the daily care of their disabled children as a challenge. It can be described as full-time-job which is both time consuming and exhaustive.

„(Die körperliche Pflege) ist mit das Anstrengendste. Baden, duschen und Zähneputzen, das ist sehr anstrengend und der größte Zeitfaktor.“ (I06; I.355)

Five of the interviewees compare the care requirements of their child with the ones of a baby who needs care for his or her whole life.

„Sie ist wie ein Baby und man muss sie wie ein Baby behandeln und versorgen und das ein Leben lang.“ (I13; I.20)

However, there are some particular situations which are further described by parents as burdening. Two mothers mention sleeping disturbances of their child as especially stressful, while four others describe screaming phases, which are partly due to perceptual disturbances, as extremely stressful.

“Es gibt Phasen wie gestern, da war eine Betreuerin da und sie ist nicht freiwillig ins Bett gegangen. Als wir nach Hause kamen um halb eins, gab das Kind immer noch keine Ruhe (...).“ (I15; I. 20)

„(Besonders belastend sind) im Moment ihre Schreiphasen. (...) Diese Schreiattacken sind bei ihr sehr laut, sehr fordernd und sie lässt sich da auch nicht beruhigen. (I11; I.348)

These previously mentioned perceptual disturbances partly lead to a restriction in family activities because affected children are unable to cope with ambient noises.

„Sie hat unser Leben sehr verändert, weil sie ganz viele Wahrnehmungsstörungen hat. Man kann im Prinzip nicht einfach irgendwo hingehen, sei es Kaffee trinken oder in den Tierpark, das war oder ist mit ihr nach wie vor eigentlich nicht machbar.“ (I12; I.45)

Another physical circumstance which enhances the parental stress level and restricts shared family activities is the problem of handling epileptic seizures which can be part of the disease pattern.

„(Freunde) sagen dann, sie fahren ins Schwimmbad oder so. Das geht bei uns nicht. Es wird immer alles kompliziert, weil wir dann erst mal packen und (...) sie dann womöglich krampft. Dann kannst du alles wieder auspacken und sagen: ‚Tut uns leid, es geht nicht‘.“ (I14; I.515)

Another factor which parents described is structuring the daily routine. It becomes obvious, that structuring the day strongly complies with the child's current health condition. Furthermore, the organisation requires a high degree of logistic planning.

„Wir müssen uns sehr an Zeiten halten und man muss sich immer nach dem Befinden des Kindes richten. Das ist ziemlich schwierig.“ (I07; I.4)

In this context, the desire for help and support in everyday needs and care came up. One mother suggested organising a service with an “emergency-number” which overstrained parents could call to get immediately help and relief.

„In dem Moment kannst du nicht sagen: ‚Ich setze mich jetzt auf die Couch und gucke Fernsehen.‘ In dem Moment hilft auch kein tiefes Durchatmen. (...) Sie haben keine Hilfe oder Anlaufstelle wo sie anrufen können um zu sagen: ‚Notfall, ich brauche jetzt jemanden der mich hier ablöst‘ und zehn Minuten später ist dann jemand da, der das übernimmt.“ (I11; I.365)

This statement clarifies the helplessness which parents partly experience in coping with the high burdens of care.

4.1.2 Communication as a challenge

Communication between parents and affected children is of great importance to achieve mutual appreciation. However, the range of communication abilities in Rett-girls is wide. In this context, two parents describe the desperation they experience because of the lacking possibilities of communication with their daughters.

„Ich würde mir wünschen, dass irgendeine Kommunikation mit ihr möglich wäre. Das wäre der größte Traum, dass sie entweder ja oder nein nicken würde, dass sie mit den Augen deutliche Zeichen geben würde oder mit den Händen. Aber da ist gar nichts.“ (I09; I.48)

The majority of parents discovered *supported communication* as an appropriate way to enhance the communication with their daughters. This technique will be further described in chapter 6.1.5.

4.1.3 Mobility as a challenge

Children with Rett syndrome are different in their mobility. While some are dependent on wheelchairs, others are agile and can move without any difficulties. High mobility is not always considered as beneficial because it requires high attention by caregivers. Parents fear that children could run away or get injured. They are always in alert and have to pay attention.

„Manchmal hätte ich mir gewünscht, dass sie gar nicht laufen kann. Dann kann sie auch nicht abhauen, aber sie ist ja überall und nirgendwo.“ (I10; l. 549)

4.1.4 Aspects of accessibility of services

Accessibility of services and medical care has an impact on the care-situation of affected children and on the requirements of the everyday-life of their parents. On the one hand, patient-centred-care seems to be diverse depending on the region. Especially rural areas have a shortage of specialized doctors and support compared to urban areas.

„Gerade für besondere Kinder gibt es hier in dieser Region eine schlechte medizinische Versorgung.“ (I04; l. 77)

On the other hand there is the problem to overcome far distances to get appropriate medical support and therapies and furthermore the time consuming frequent doctor consultations which were mentioned many times.

„Damals bin ich (...) in einem Jahr fast 37.000 km gefahren, nur an Therapiefahrten.“ (I06; l. 238)

4.1.5 Structural circumstances

Two parents criticize the built urban environment as unsuitable and inaccessible with wheelchairs.

„(...) Da gibt es dann keinen Fahrstuhl, nur Treppen. Mit Rolli ist das natürlich nicht möglich oder es gibt keine Schiebetüren.“ (I11; l. 424)

4.1.6 Potential relief

Mostly, parents experience relief from common challenges by their partners and families in general. They feel supported by them and they also adopt the care of the disabled child partially.

“Wir sind eine sehr starke Familie und haben einen starken Familienzusammenhalt. (...) Wir haben meine Schwägerin oder Schwester, bzw. Schwiegereltern oder Mutter, die dann mal einspringen. Wir haben uns damit ein sehr enges Netzwerk geflochten.“ (I06; l. 175)

Many parents report on using external support like family support services⁴ or short-term care services⁵ rather than support by their families. This kind of support also relieves them from their daily routine and gives them the opportunity to increase their time for recreation or employment.

„Wir haben hier eine gute Kurzzeitpflege, wo ich sie auch mal am Wochenende hinbringen kann. Es gibt dann auch noch einen familienentlastenden Dienst, so dass man sich dann auch seine Freiräume schaffen kann.“ (I01; l. 145)

Other parents report that the right to care support is linked to the allocation of care levels and the appending care allowance. One mother describes support at home by babysitters, nurses or nannies, which allows some flexibility and time off. This support is possible because of the child's allocation to care-level 3.

„Wir haben dadurch, dass sie Pflegestufe 3 hat und wir Betreuungsgelder über die Kasse abrechnen können (...), von Anfang an Studenten gehabt, die auf sie aufgepasst haben.“ (I15; l. 416)

Another factor which disburdens parents is the offer of therapies like physiotherapy, occupational therapy or speech therapy at schools. Children with Rett-syndrom often need a range of different therapies. This can be exhausting in terms of mobility and costly in terms of time and money for parents. During the last years there is an increase in schools which bundle different types of therapies and

⁴ Service for families with disabled children which offers support in recreational activities and in child care (mostly linked on larger providers care providers) (Engelbert & Schwarze 2010)

⁵ Temporary child-care in a fulltime-care facility as benefit of health insurances or social assistance authorities (Diakonie Hamburg 2013)

provide them in-house. This alteration allows parents to spend the gained time and money for other important tasks of their daily routine.

„In der Schule hatten wir das Glück, dass (Therapien) gebündelt wurden, zum Beispiel wurde die Krankengymnastik im Stundenplan mit abgehandelt. Das wurde uns also von zu Hause abgenommen. Genauso wie Schwimm- und Reittherapie (...), das hat uns ganz viel Luft gegeben.“ (I06; l. 234)

Another factor which gained importance over the last years is *supported communication*⁶. Almost all parents entirely rate supported communication as helpful and supportive for enhancing the communication and the living together with their child.

„Wir haben fast alle UK (unterstützte Kommunikation, N.St.) als eine der wichtigsten Therapien für uns entdeckt, weil es allen Beteiligten die höchste Lebensqualität bringt. Es gibt nichts Besseres, als mit dem Kind reden zu können. Seitdem (...) hat sich auch unsere Tochter anders entwickelt, sie ist viel zugewandter geworden. (...) Sie kann ganz anders agieren und zeigen, was in ihr steckt.“ (I15; l. 470)

However, two parents who use *supported communication*, criticize a lack of trained therapists who could teach them how to establish the techniques appropriately.

„UK (Unterstützte Kommunikation, N.St.) ist schon im Kommen, aber Sie müssen auch die Therapeuten dazu finden.“ (I01; l. 480)

One parent mentioned a special technique which she discovered as very helpful: Kinaesthetics. Kinaesthetics is based on the experience and perception of a

⁶ This term summarises all pedagogic and therapeutic methods to extend the communication skills of people who are not able to speak. Examples which are often used for working with girls with Rett syndrome are symbol-cards or so called “talkers” which are specific speech-processors (Rothmayr 2001)

person's own movement and leads to an increased awareness for the quality and differences of own movements. This technique has refined and catered to the needs of caring relatives during the last years⁷.

„Wir haben in unserer Gruppe noch einen Ansatz verfolgt, um die körperliche Belastung der Eltern ein bisschen zu mindern: Wir haben uns mit Kinästhetik befasst. Das ist eine spezielle Art des Handlings mit Pflegenden, dort sehe ich ein großes Potential.“ (I03; l. 464)

Almost all parents mentioned the support by parental self-help groups as relieving and helpful but also highlight its importance for finding therapies, benefits or appropriate medical and social support. Some parents mention the exchange of knowledge and personal experience as particularly important for their own condition.

„Wir sind schnell auf die Elternhilfe gestoßen und die waren für uns der erste Ansprechpartner. Seitdem haben wir die meisten Informationen von dort. Natürlich auch über das Netzwerk innerhalb der Elternhilfe: Jeder weiß was und hat was zu berichten, das ist absolut unschätzbar.“ (I03; l. 400)

One parent, who is also part of the steering committee of a parental initiative, highlights the problems and constraints some parents have in making use of the expertise of such an initiative.

„Wir merken immer noch, dass einige Eltern aus Zeitmangel, aus Schamgefühl oder was auch immer, sich überhaupt gar nicht bei der Elternhilfe melden mögen.“ (I06; l. 416)

⁷ Caregivers learn how to effectively apply own movements and movements of the disabled child to relieve themselves and thereby to facilitate daily care (Woydack 2013)

4.1.7 Everyday-life of caregivers in a nutshell

Coping with requirements of the everyday-life is a challenge for most parents. Especially the physical care is a burden and demands a lot of time and effort. Children are mostly on the mental state of a baby which increases the challenges of care. Disability-specific behaviours like sleeping disturbances, screaming phases, perceptual disturbances or epileptic seizures additionally complicate the daily routine with a Rett-child and restrict families in shared family activities. Furthermore, all these manifold impairments and afflicted requirements make it hard for parents to establish a structured daily routine. Therefore, there is the call for support in these tasks of daily routine because structuring the day requires a lot of organisation.

The lack of communication skills and the severe problems in understanding each other have great impact on the parental quality of life. Also the different mobility statuses can be challenging: The more mobile the child is the more attention needs to be paid to protect them from injuries or from getting lost.

There are regional differences in medical and therapeutic support. Especially rural and suburban areas have a lack of appropriate support for disabled children. This undersupply in some areas leads to a high burden of care for parents because they have to overcome far distances and also need to be mobile to reach medical support. Relating to structural circumstances parents of children in wheelchairs complain about public facilities which are not handicapped accessible.

Parents try to get some relief from their everyday challenges. Some use the family as internal support system while others use external support by family support services, short-term care services, babysitters/ nannies (depending on the allocation of care levels and therefore on availability of care allowances) or networks of parental initiatives. Parental initiatives and self-help groups are considered as helpful and supportive by almost all parents. Here they can exchange knowledge and experience and get help in seeking information about disease, therapies or disease-related problems and solutions.

Improvements in the school system also lead to potential relief of parents. Nowadays many schools bundle different therapeutic offers in-house. This saves time, money and effort for affected parents.

To improve communication with their children, many parents discovered supported communication as appropriate method to enhance interactions with each other. This disburdens them because they get a better understanding of their child its requests and demands. However there is still a lack in well-educated trainers who could cover the increasing demand in support.

4.2 Formal support and strains

This chapter summarizes all statements elaborating on external support. It also covers situations with support services, medical staff and insufficient information but also problem in receiving and accepting the diagnosis "Rett syndrome".

4.2.1 Late diagnosis

The majority of parents describe the late diagnosis of the Rett syndrome as severe burden. Since the symptoms of the Rett syndrome can be diverse some doctors tend to misdiagnose or hesitate with their definite diagnosis. The resulting uncertainty increases parental anxiety. In many cases, the diagnosis was unclear for quite a long time. In the end, many parents experience the reception of the final diagnosis as relief because they could explain specific behaviours of their child which are due to the Rett syndrome and are not ambiguous about the reasons for these extraordinary patterns.

„Wir waren froh, als endlich die Diagnose kam. Dann konnten wir erklären, warum sie schreit: ‚Das gehört zum Rett dazu. (...) Das ist ganz typisch für dieses Krankheitsbild.‘ Davor stand man hilflos da: Warum schreit sie jetzt?“ (I01; I. 264)

Five parents describe how stressful they experienced the odyssey of finding the right diagnosis: It was afflicted with endless hospital visits and examinations which were exhaustive for the parents as well as for the child.

„Der Kinderarzt hat uns an die Uniklinik überwiesen und da war es ein Untersuchungsmarathon. Mit einem Jahr sind wir mit dem Verdacht dorthin und mit drei Jahren haben wir dann die Diagnose bekommen. Zwei Jahre sind wir

immer wieder in Krankenhäuser gefahren und haben alle möglichen Tests gemacht.“ (I07; l. 133)

Parents also describe, that the situation of late diagnosis has changed over the last years. Diagnostics are improved, largely due to the development of a new blood test⁸.

„Das Wissen, das man über das Rett Syndrom heute hat ist völlig anders, als das was wir vor 30 Jahren hatten. Das sagen auch die Ärzte selber. Inzwischen gibt es einen klinischen Marker, das macht vieles einfacher.“ (I02; l. 250)

4.2.2 Disease-specific information

Half of the parents experience a lack of expert knowledge in doctors with respect to the Rett syndrome and its progress.

„Es gibt immer noch viel zu wenige Ärzte, die wirklich Bescheid wissen.“ (I15; l. 796)

Contrariwise three parents report an improvement of disease-specific knowledge in health experts during the last years which partly results from public awareness rising by parental initiatives and organisations.

„Wir treffen immer mehr Ärzte und Therapeuten, die tatsächlich etwas mit dem Rett Syndrom anfangen können. Da haben wir schon das Gefühl, dass die Öffentlichkeitsarbeit (der Selbsthilfegruppe) wirklich Früchte trägt.“ (I08; l. 42)

Another factor which was mentioned is the lack in sufficient transfer of information about the disease, its progress and about legal claims in care support which parents could demand. More than half of the parents feel unsupported.

⁸ Since 1999 the MECP2-Gene can be tested via blood test. By finding a mutation the diagnosis is confirmed. However 5% of children with Rett syndrome show no gene-mutation (Elternhilfe Rett-Syndrom 2013)

„Am schlimmsten finde ich, dass man nicht weiß was einem zusteht. (...) Das das Kind zum Beispiel, wenn es über ein bestimmtes Alter hinaus kommt und Windeln braucht, diese von der Krankenkasse bezahlt werden. (...) Es ist so mühsam, wenn man am Anfang steht und keiner einem hilft oder man nicht weiß, wo man fragen kann. Man steht da und hat ein Kind, das anders ist, aber es kommt von nirgends Hilfe.“ (I14; I. 633)

The majority of parents searched disease-specific information on their own mostly in the internet. There is a great desire and need for support in seeking information. Parents also report the need of coordination centres or leaflets which offer sufficient information particularly with regard to possible support offers, where to get them, contact-points and rights. One mother specifies these demands by proposing the introduction of a disability representative.

„Es gibt leider keinen Behindertenbeauftragten, der sagt was Ihnen zusteht und wo Sie was kriegen (...). Wenn man eine Zentrale hätte, die einem das sagen würde, einen Behindertenbeauftragten, der das alles koordinieren würde, das wäre sehr hilfreich.“ (I11; I. 670)

4.2.3 Health professionals behaviour

Half of the parents criticised the lack of empathy they experienced in discussions with doctors and health professionals. This leads to feelings of hopelessness and frustration.

The way the diagnosis was communicated to parents was described as inadequate four times.

„Der Arzt hat sich damals ganz schlecht benommen. (...) Der (...) kam rein und hat gesagt: ‚Ihre Tochter hat das Rett Syndrom und Sie müssen damit rechnen, dass sie in der nächsten Zeit epileptische Anfälle hat.‘ Dann hat er sich umgedreht und ist gegangen.“ (I04; I. 94)

„Die haben uns eine Rechnung geschickt mit der Überschrift: Diagnose Rett. Da haben wir erst mal nicht glauben können, dass das jetzt die Mitteilung sein sollte,

dass es tatsächlich das Rett Syndrom ist. (...) Dann kam ein Anruf, wo sie sich dafür entschuldigt haben, dass das Schreiben aus Versehen früher kam als das Eröffnungsgespräch. Das war ziemlich übel. (...). Da war niemand da, der uns auch nur annähernd hat auffangen können.“ (I08; I. 75)

4.2.4 Short-term care and fulltime-care facilities

Other big issues mentioned in almost every interview are quality and availability of short-term care services and fulltime-care facilities, a lack of adequate nursing care places and long waiting lists.

„Zu wenige Plätze sind es auf jeden Fall. (...) Zu Beginn konnte ich (...) da anrufen und fragen: ‚Habt ihr am Wochenende Platz für mein Kind?‘ Das hat sich inzwischen aber gewandelt. Es ist etabliert und dauert bisweilen schon länger, bis man einen Platz bekommt.“ (I01; I.165)

Another point criticized by several parents is insufficient care in such facilities, especially the deficient patient-nurse ratio.

„Ich habe viele Einrichtungen angesehen (...). Da ist die nächtliche Betreuung nicht gewährleistet, auf den Fluren ist kein Personal, alles ist viel zu eng. (...) In der Nacht sind für 3 Etagen zwei Pfleger da.“ (I03; I. 228)

As possible reason for this insufficient patient-staff-ratio two parents mention the lack of money to employ additional staff.

„Ich habe in verschiedenen Einrichtungen nachgefragt und die haben gesagt: ‚Es ist einfach nicht genug Geld da, um eine bessere personelle Versorgung zu gewährleisten‘.“ (I03; I. 245)

One mother reports her mistrust in care facilities because she heard about misuse in such facilities. This fact prevents her from handing her child over into such a facility.

„Ich weiß von Eltern in der Elternhilfe, dass da ein Missbrauch stattgefunden hat. In wieweit weiß ich nicht, aber es wurde von blauen Flecken und dergleichen gesprochen. Dann machen Sie sich natürlich Gedanken.“ (I11; I. 441)

Two parents criticize the caring approach of these facilities, which they describe as strongly focussed on basic care without considering social aspects which are important for holistic care. Furthermore, short-term care is in large part adopted by nursing homes, specific facilities for children and adolescents are rare. This is why care is aimed at the needs of elderly people in high-maintenance without considering the requirements of children; therefore some parents prefer to seek a babysitter or nanny on their own to support them.

„(Babysitter) können unsere Tochter auch bespaßen und ablenken. So ein professioneller Pflegedienst macht das nicht. Die sind nur auf alte Leute ausgelegt, die machen dann nur Grundpflege, legen sie ins Bett und das war es dann. (...) Das Zwischenmenschliche kommt zu kurz.“ (I11; I. 254)

This uncertainty of getting appropriate nursing care places burdens parents. In this regard one mother claims the guarantee that every child gets an appropriate nursing care place in a facility within one year.

„Wünschenswert wäre eine Pflegeeinrichtung, wo man sich drauf verlassen kann, dass man das im Laufe des Jahres auch einen Platz kriegt.“ (I11; I. 599)

4.2.5 Nursing staff

Although the support by nursing and care services is widely seen as relief, three parents criticize the constant change of nurses who foster their child. On the one hand this change forces them to permanently repeat their care instruction which is exhaustive; on the other hand it hinders trust building between the child and the nurse which is important to assure an optimal care.

„Man bräuchte einen Pflegedienst, der immer die gleiche Pflegekraft schickt. Oft ist es so: Heute kommt die Eine, morgen die Andere. Rett-Mädchen bauen aber

auf Kontinuität auf. (...) Sobald jemand etwas anders macht sind sie völlig orientierungslos und blockieren. Das ist natürlich absolut schwierig hinzubekommen.“ (I06; I. 366)

There is another issue which was raised in half of the interviews: The insufficient disease-specific education of nursing staff. This lack of knowledge makes it difficult to handle the complex care requirements which are afflicted with the Rett syndrome. It becomes clear that not only appropriate education is important but also high nonverbal communication skills, sensitiveness and empathy.

„Das Pflegepersonal muss besser ausgebildet werden. (...) Gerade für unsere Kinder, die haben keine Kommunikation. Die brauchen jemanden mit Feingefühl, der sich in die Situation hineinversetzen bzw. Körpersprache lesen kann und das können die Wenigsten.“ (I06; I. 398)

Care of children with Rett syndrome is a challenge for common healthcare professionals. One parent proposes the introduction of specialized Rett-nurses⁹ based on an American model. This holistic care approach guarantees best possible care for the children because it does not only focus on physical symptoms but also on social aspects of care.

„Die Amerikaner haben eine Zusatzqualifikation als Rett-Nurse. Da wird Nurse aber nicht verstanden im Sinne von Krankenschwester, sondern als Rundumbetreuerin, inklusive soziale Aspekte und Versicherungsfragen. (...) Sie ist auch Vermittlerin zwischen Arzt und Patient, hat Spezialkenntnisse und weiß eben, was diese Rett-Patienten und die Familien brauchen.“ (I02; I. 626)

⁹Rett-nurses are involved in the enrolment and follow-up care of the patients who might be diagnosed with Rett syndrome. They are contact persons for parents who require information or advice regarding medical care, therapies and legal rights of their child (Blue Bird Cycle Rett Center 2013)

4.2.6 Services by health insurances

Satisfaction with service provision of health insurances in parents is diverse. Most report problems in applying for assumptions of costs if the required service exceeds standards defined by health insurances. Some services are only achievable by constant objections. This process is described as complex, exhausting and time-consuming.

„Einige Pflege- und Heilmittel (...) sind nur über das Widerspruchsverfahren zu erlangen. Das kostet sehr viel Kraft und Zeit, die man eigentlich nötiger für sein Kind bräuchte und nicht, um am Schreibtisch zu sitzen und Widersprüche zu schreiben.“ (I06; l. 160)

It was criticised that costs are accepted for standard benefits indeed, but additional costs for helpful care appliances are not taken over by health insurances.

„Man benötigt doch viele Kleinigkeiten und (...) Hilfsmittel, die von der Krankenkasse nicht übernommen werden, einem das Leben aber unheimlich erleichtern.“ (I04; l. 288)

One benefit which is described many times as extremely helpful in decreasing and attenuate scoliosis but not reimbursable by health insurances is the Hippo-therapy¹⁰. This therapy was mentioned by four parents as something which should be necessarily included into the scope of services.

„Was von den Krankenkassen gar nicht gezahlt wird, aber das Hilfreichste bei unseren Mädchen ist, ist die Reittherapie. Das ist eigentlich das wirkungsvollste Mittel gegen eine Skoliose. Das wird nicht gezahlt, aber die teure Skoliose-OP.“ (I01 l. 366)

¹⁰ Hippo-therapy is a form of therapeutic riding with specific trained horses. It is a physiotherapeutic method which is applied in persons with diseases of the central nervous system and musculoskeletal-system (Gutenbrunner 2003)

This statement clarifies that also the allocation of reimbursements is experienced as unfounded especially with regard to resulting expenditures for health insurances.

One parent claims more flexibility of health insurances relating to the reimbursement of expenditures, which are of importance to improve the situation their insurants.

„Die Krankenkasse sollte mal nachdenken, was im Sinne der Versicherten wäre und ihnen da weniger Steine in den Weg legen. Das man den Leuten nicht von Vornherein sagt: ‚Machen wir nicht, steht nicht in den Regeln.‘“ (I02; I. 603)

4.2.7 Application for Care Levels

Three parents report problems in applying for care levels. The needs-assessment by the medical service of the health insurances was experienced as problematic and challenging.

„Das ist für mich eigentlich eine Selbstverständlichkeit, dass der MDK (Medizinische Dienst der Krankenkasse, N.St.) kommt und sagt: ‚Ich sehe, dass das Kind nichts kann. Es muss voll betreut werden, die Pflegestufe wird eingeteilt.‘ Nein! Da werden fiese Fragen gestellt, so dass man teilweise Antworten gibt und einem fünf Minuten Pflegezeit fehlen und dann kriegt man die Pflegestufe nicht.“ (I04; I. 352)

4.2.8 School situations

The majority of parents are satisfied with the school situation of their children and school staff education. But there are some points of critique mentioned.

Two parents refer to the teachers' knowledge relating to the commitment of supported communication as insufficient.

„Man kann nicht sagen, dass es wirklich eine Schule ist, in der das Personal auf UK (Unterstützte Kommunikation, N.St.) eingestellt ist. Aber es gibt immer mehr Lehrer, die bereit und in der Lage sind sich weiterzubilden.“ (I15; I. 132)

Some Rett-girls have integration supervisors¹¹ at school to help them manage the school routine. Especially if they are very mobile they need someone to pay attention to them. Some parents are not content with the way how this support is implemented in schools. Reasons for dissatisfaction are a lack of motivation or education of the supporting staff or the wrong deployment of this person in areas which are not in his or her field of duty.

„Letztendlich habe ich festgestellt, dass die Integrationskraft nur dazu genutzt wurde, um das Personal aufzupuffern. Das ist kein Einzelfall. Ich höre das immer wieder, dass das Personal über Integrationshilfen aufgestockt wird und die letztendlich gar nicht eins-zu-eins für das zugewiesene Kind eingesetzt werden, sondern auch ganz andere Aufgaben übernehmen.“ (I01; I.72)

Another challenge which was mentioned once is the lack of support programs for the children combined with the unwillingness of teachers to develop such concepts.

„Dann sollte ich zu einem Elternabend kommen und habe mich ein bisschen erkundigt, wo das Förderkonzept für meine Tochter ist. Die haben dann gesagt: ‚Wieso Förderkonzept?‘“ (I02; I. 89)

4.2.9 Formal support and strains of parents in a nutshell

Parents report on multifaceted problems in formal support. A big issue is the late diagnosis which increases fear and helplessness. The fact that doctors' disability-specific knowledge sometimes is insufficient leads to odysseys of examinations and clinic visits. Nowadays, the situation has changed and diagnostics are easier due to the development of a blood test. The parental initiatives enhance knowledge about the Rett-syndrome by raising public awareness during the last years. Parents feel unsupported in finding appropriate information with regard to the disease, benefits, legal claims, and therapies. To facilitate this situation,

¹¹ Integration supervisors undertake the task of support in care and assistance at school by structural support (e.g. guiding the hands), emotional and social support (e.g. pacification) and support in communication (Bayrisches Staatsministerium für Unterricht und Kultus 2008)

parents propose the initiation of coordination centres or leaflets which cover all these topics. One suggestion is the introduction of a disability representative who acts as contact person for all disability-related questions. Parents experienced the behaviour of health professionals as rude and less empathetic especially with regard to the communication of diagnosis. Largely criticised is the situation with short-term care and fulltime-care facilities. Parents are dissatisfied with its availability, quality and long waiting lists. Furthermore, the patient-staff-ratio in some facilities is insufficient so that adequate care is not ensured. The non-holistic caring approach with a strong focus on elderly high-maintenance people is also an issue because respite care is largely adopted by common nursing homes. These nursing homes focus on primary health care rather than on individual care adapted to children's special needs. Nurses are criticized in two ways: On the one hand there is a constant fluctuation of nursing staff which leads to feelings of insecurity and mistrust in parents but also in the affected child. On the other hand nurses tend to have a lack of disease specific knowledge and required sensitiveness which is needed to guarantee optimal care for Rett-children with their specific needs. Another issue which was raised is the problem to get appropriate benefits by health insurances, especially if they exceed standard reimbursements. Some benefits are only assessable by objection. This process is experienced as exhaustive and time consuming. In this context the high advantages of hippo therapy were highlighted which is also not included in the scope of service. One father claims more flexibility towards insurants to meet their demands as best as possible. Possible problems in applying for care levels dependent on the assessor of the Medical Review Board of the Statutory Health Insurance Funds which assesses the need of care. Some parents report back-stabbing questions which in the end foreclose the classification into a higher care level. With regard to schools most parents are satisfied with the situation and teachers. Only a small number criticize the teacher-student-ratio while others are dissatisfied with the knowledge in respect of supported communication. Also the wrong deployment of integration advisors for other tasks than care of the disabled child was mentioned critically.

4.3 Financial barriers

This chapter summarizes all statements which are linked to the labour situation of parents, disease-specific expenses and the financial situation as such.

4.3.1 Labour situation

The majority of parents report they reduced their working hours or quit their jobs due to the disability of their child. Due to temporal or psychological aspects they are not able to continue working in their usual manner. Changes in employment mostly affect women because they are caregivers for their disabled children in most instances.

„Ich habe Vollzeit gearbeitet (...) und jetzt arbeite ich zwei Tage. Mehr würde ich zeitlich gar nicht schaffen und die Kraft fehlt mir.“ (I08; I. 27)

A minority of parents experience the impact of these financial changes as burdening, while most of them do not perceive restrictions in their previous lifestyle. This is depending on the partners' income.

„Berufstätigkeit ist für mich wegen der Kinderzahl und Pflege kaum machbar. Mein Mann ist nur Leiharbeiter, (...) das reicht halt nicht für Urlaube und große Extras.“ (I09; I. 224)

„Ich habe meine Arbeitszeit reduziert, (...) aber finanzielle Probleme haben wir nicht. Mein Mann verdient recht gut.“ (I10; I88)

Two parents report that going to work also compensated from daily care challenges.

„Ich arbeite in einem Hofladen mit (...). Ich sehe es auch als Ausgleich: Es macht Spaß, ist schön und das möchte ich jetzt auch nicht missen.“ (I12; I. 342)

4.3.2 Care allowance of parental nursing care

Another factor which influences the financial situation is insufficient care allowance for parental nursing care¹² compared to high payments of care allowance for care in nursing homes. Parents suggest that the time for nursing a disabled child should be also credited of pensions.

„Wenn die Pflegezeiten besser honoriert werden (...) und auf die Rente angerechnet würden, dann wäre ein großes Problem weniger. Denn: Warum kriegt ein Heim oder der Pflegedienst das Vierfache von dem, was die Eltern kriegen? Wir kriegen nur die Pflegestufe, mehr nicht.“ (I11; I.51)

4.3.3 Additional costs

Some parents report additional costs which are linked to the disability of their child. Three of them report on architectural changes they had to undertake to make their homes handicapped assessable.

„Wir haben gerade frisch angebaut, alles behindertengerecht. Sie hat ein eigenes Zimmer mit behindertengerechtem Badezimmer.“ (I06; I. 209)

Two parents mention additional equipment acquisitions like shoes as a custom product or special nutrition as extra charges.

„Man kriegt nicht alles bezahlt, was eigentlich für die Kinder notwendig ist. Die haben dann zum Beispiel auch manchmal spezielle Ernährung, das ist auch sehr kostenintensiv.“ (I03; I. 204)

¹² Care allowance for nursing care monthly: level 1: 305 E; level 2: 525 E; level 3: 700 E;

Care allowance for care in nursing homes (ambulant treatment): care level 1: 665 E; care level 2: 1250 E; care level 3: 1550 E

(Kruse 2013)

4.3.4 Financial barriers in an nutshell

Financial barriers are described by parents in different ways. In parental couples one partner, often the mothers, have to reduce working hours or even quit their jobs to manage daily challenges of care. Only some experience reductions in their standard of living. How the lacking second income impact the parental life is strongly linked to the partners' income.

Caring parents who still work consider this employment as compensation for their daily care-routine. It was criticized that nursing care by parents is poorly paid although it is a full-time job. Furthermore the adoption of care at home is cheaper for health insurances than health care utilization.

The care of a child with Rett syndrome is afflicted with additional costs which are not covered by health insurances. Commodity items like shoe inlays or specific nutrition but also architectural alterations like wheelchair-ramps or handicapped accessible housing are cost-intensive and can burden families severely.

4.4 Personal health

This chapter summarizes all statements elaborating on personal health of parents. It covers the mental and physical status but also situations which emotionally affects parents.

4.4.1 Time for recreation

There are three parents who criticize that they have no time for recreation which really burdens them and reduces their quality of life.

„Mein Leben? Ich habe eigentlich gar kein eigenes Leben mehr. Ich bin eigentlich nur Hausfrau, Mutter, Tierverwalterin und Pflegerin. Mehr ist da nicht mehr.“ (I09; I. 134)

This statement highlights the desperation and resignation some parents experience due to their restricted stress relief.

However the majority of parents tried to take their time for relaxation. It becomes apparent how important this relieve is to cope with the daily requirements of care.

„Wir fahren alleine in den Urlaub, denn diese 14 Tage im Jahr müssen wir wirklich haben, damit wir wieder fit sind. Da hat sie dann auch mehr von, wenn wir wiederkommen und entspannter sind.“ (I14; I. 432)

One parent highlights the importance of what she calls „healthy egoism“ in regard of the fact that parents have only one life to live, too.

„Man muss einen gesunden Egoismus entwickeln, denn man darf eins nicht vergessen: Man hat nur ein Leben (...). Man ist plötzlich in diese Situation gerutscht und musste sich arrangieren. Und arrangieren heißt: Jeder muss Kompromisse eingehen, auch das behinderte Kind.“ (I06; I. 302)

4.4.2 Psychological situation

Many parents report psychological burdens they experienced during the course of disease. The most common burden mentioned in four cases is depression.

„Bei mir ist zum Beispiel so ein richtig ausgeprägter Winterblues (...), mit diesen ganzen Grübeleien. Es ist schon eine psychische Belastung.“ (I01; I. 393)

Three parents describe the mental situation more as a feeling of excessive demands and pressure especially if unexpected, challenging situations occur.

„Wir hatten jetzt gerade eine Krankheitsphase, da bin ich echt auf dem Zahnfleisch gekrochen. Da hab ich ihren Vater angerufen und gesagt: „Du musst sie jetzt nehmen, jetzt bist du dran. Ich kann nicht mehr.“ (I07; I. 176)

This statement illustrates the importance of support to overcome burdens of care. Another physical problem which was mentioned twice is sleeping disturbance which can be attributed to the constant readiness the parents are in.

„Die Nächte sind kürzer, denn sie hören jedes Knirschen, jedes Atmen. Sie lauschen erst mal: Muss ich aufstehen, muss ich nicht aufstehen? Ist das jetzt

ernst? Sie gucken dann auf jeden Fall nach und brauchen dann wieder eine gewisse Zeit, bis sie einschlafen.“ (I11; l. 158)

There is a call for better psychological support for parents, especially after they get the diagnosis. Three of the interviewees mentioned there was no offer of psychological help even though they could have benefited of it.

„Wenn dann jemand in ein tiefes Loch fällt, wird einem keine psychologische Unterstützung angeboten. Da denkt man sich: Das wäre doch vielleicht schon mal eine Hilfe, wenn man sagt: ‚Sie können dies und das gleich in Anspruch nehmen‘.“ (I12; l. 213)

Referring to this, one parent describes an approach of her psychologist which really helped her and her family to cope with the situation and to overcome psychological burdens: He considered the family as a system. This clarifies how helpful psychological support could be.

„Der (Psychologe) hat die Familie als System im Blick gehabt und hat meinem Mann und mich mit eingebunden: Wer übernimmt was? Wer hat welche Kraft für welche Aufgabe? Wo ist der Bruder und wer kümmert sich um ihn? Wo ist sein Platz? Das war super und ist das wovon wir heute, nach den acht Jahren, noch zehren.“ (I08; l. 28)

This statement clarifies that a disability not only impacts the affected child but also the whole family so that everyone should be included in the development and implementation of psychological support.

4.4.3 Physical situation

To care for a child with Rett syndrome can be afflicted with physical problems. Half of the parents report musculoskeletal diseases which can be ascribed to the challenges of care.

„Ich merke es auf der körperlichen Ebene schon mal durch Schulterschmerzen oder Knieschmerzen“. (I11; l. 547)

The development of musculoskeletal diseases is mostly associated with a problem mentioned in category 1: The fact that many children are in the mental stage of babies. Therefore they are reliant on parental support like carrying or lifting even if they already have the weight of young women.

4.4.4 Personal health of parents in a nutshell

One big issue concerning parents' personal health is the lack of time for themselves and therefore the lack of recreation. Creating the necessary flexibility requires planning but is considered as important by almost all parents. Taking time serves as "charging the batteries" which positively impacts both parents and as a consequence as well as the disabled children.

High requirements of care combined with the lack of recreation can lead to psychological problems. Frequently mentioned are depressions, the feeling of exhaustion and sleep disturbances. The call for psychological support especially during the time of diagnosis becomes apparent to help parents to better cope with the situation.

Musculoskeletal diseases can also be a result of caring for a child with Rett syndrome. Depending on the child's mobility lifting and carrying can negatively influence the development of these diseases.

4.5 Familial and social support and strains

This chapter summarizes all statements elaborating on social and familial impacts the disability has on parental life. It also includes the description of social relationships with siblings, partners and friends.

4.5.1 Time for leisure/social life

The majority of parents describe a lack of time for social activities as burdening. Due to the disability common leisure activities are hard to organize for the family

together as well as for the parents as couple. Depending on the mobility of the child, some parents feel confined indoors because planning activities without involving the child are afflicted with high organizational expenditures.

„Für mich ist das Entscheidende, dass Eltern mehr Freizeit gewährt wird. Dass die Last abgenommen wird, um auch eigene Dinge zu machen und dass man nicht so angebunden ist. (...) Dass man auch Zeiten hat, in denen man mal für sich ist. Oder ein Nachmittag, wo man gemeinsam an den Strand fährt, bummeln geht oder einfach mal die Seele baumeln lässt, ohne immer auf die Uhr zu gucken.“ (I04; I. 405)

„Sie müssen jeden Freiraum organisieren. Da ist ja ein Vorlauf: Haben Sie einen Babysitter? Was machen Sie und für wie lange? Kann das der Babysitter? Brauchen wir eine Kurzzeitpflege und ist diese okay?“ (I11; I. 202)

With respect to the minor leisure time, three parents remark their desire for expansion of short term care times.

„Man sollte vor allem mehr Betreuungszeiten ermöglichen, weil die den Eltern wirklich Entlastung bieten.“ (I08; I. 204)

4.5.2 Societal exposure to the disability

Parents experience the way society copes with the disability very differently. Three interviewees have the feeling that being disabled is still considered as a blemish.

„Tragischerweise ist es so, das finde ich sehr schade, dass es immer noch Leute gibt, die (...) die Behinderung als ein Makel ansehen oder als eine Brandmarkung.“ (I06; I. 93)

The way on how parents experience the gazes of outsiders are also quite diverse. While half of them experience it as aggravating, stigmatizing and inappropriate, the other half registers gazes but considers it as natural.

„Die Leute gucken immer so doof. Es kommt aber auch auf meine eigene Verfassung an. Manchmal ist es mir egal und manchmal rege ich mich auf und denke mir: ‚Wo ist die Tarnkappe?‘.“ (I08; I. 174)

„Es wird mal geguckt, aber nur fünf Minuten und dann wird sich umgedreht. Man muss offen mit der Behinderung umgehen. Wenn man eine offene Ausstrahlung hat, dann sprechen einen die Leute einfach an und dann erzählt man denen was und dann ist gut. Aber wenn man sich zurückzieht in sein Schneckenhaus, dann haben die Leute auch Hemmungen einen anzusprechen.“ (I04; I. 245)

One mother criticizes the lack of consideration by outsiders in public places.

„Die Passanten laufen alle mit Scheuklappen durch die Welt, gucken nicht nach links und rechts und machen mal die Tür auf. Man muss immer gezielt die Hilfe einfordern.“ (I11; I. 426)

Another parent criticizes the commiserations by strangers. For her the child should be considered as a normal child without reducing his/her on deficiencies.

„Ich habe mal in der Straßenbahn eine ältere Dame getroffen, die hat gesagt: ‚Sie tun mir so leid‘. Da habe ich gesagt: ‚Wieso tue ich Ihnen leid? Da muss ich Ihnen nicht leid tun, hauptsache das Kind ist glücklich‘.“ (I13; I. 136)

4.5.3 Guilt and reproach

Many parents have to fight social prejudices and reproach. Two of them talked about the assignment of guilt for the disability by their families. This leads to quarrels within the family and is a high burden for affected parents.

„Meine Schwiegereltern können nicht akzeptieren, dass in unserer Familie jetzt jemand behindert ist. Die suchen immer den Fehler, von welcher Seite das kommt und sagen dann: ‚Das kommt nicht aus unserer Familie, bei uns sind keine Behinderten‘.“ (I14; I. 394)

Two other parents report allegation of neglect or lacking education of their child.

„Bei uns in der Familie gab es die Diskussion, dass wir unsere Tochter vernachlässigt hätten und es sei so eine Art Gehirnschädigung durch Vernachlässigung. Das ist natürlich die Frage nach Schuld.“ (I02; I. 291)

Another extreme example which was described by a mother was an accusation of abuse. This really burdens her because this reproach was brought up at a time she had had no definite diagnosis and no explanations for the strange behaviour of her daughter.

„Alle haben gedacht ich misshandle mein Kind, weil sie nur geschrieen hat. Das sind immer Phasen bei Rett Kindern, aber das wussten wir damals noch nicht. Da wollten sie mir das Münchhausensyndrom unterstellen.“ (I13; I. 26)

In two other cases, outsiders blame parents that they live on welfare or receive support because they do not work.

„Die sehen: ‚Sie fährt jetzt ein dickes Auto.‘ Ja, ich brauch auch das Auto, um das Kind mit dem Equipment von A nach B zu bekommen. Dann hören sie: ‚Die kriegt Pflegegeld.‘ Man hat das Gefühl, dass die denken: ‚Die macht sich einen schönen Lenz auf Kosten der Pflegeversicherung oder Vater Staat.‘ (I01; I. 122)

One parent describes reproach by her family and friends because she handed the child over into a care facility.

„Mit dem Wechsel aus der Familie in die Einrichtung gab es Leute, die gesagt haben: ‚Was seid ihr für Rabeneltern? Wie könnt ihr euer behindertes Kind weggeben?‘ Wir haben sie nicht weg gegeben. Wir haben sie in eine Einrichtung gegeben, um ihr eine Perspektive zu geben.“ (I02; I. 326)

4.5.4 Acceptance of the disability

Accepting, that the child has a severe multiple disability is hard for almost all of the parents. The particular challenge of accepting this disability is that the formerly healthy child suddenly loses most of its skills and motor abilities. This is something which really shocks the parents.

„Die Behinderung zu akzeptieren war schwer. (...) Einfach die Tatsache, dass sie von jetzt auf gleich schwerst mehrfachbehindert sein wird. Nicht nur, dass man sagt: ‚Sie hat jetzt eine leichte Behinderung‘. Aber die Tatsache, dass sie irgendwann gar nichts mehr können wird (...).“ (I12; l. 218)

Not only parents themselves have to find ways to cope with the situation, also the whole family is confronted with a totally new situation. Three interviewees report that family members have problems accepting the child's disability and try to avoid contact. This fact heavily burdens affected parents and gives them the feeling of suspension.

„Mein Schwager hat zwei kleine Mädchen, das sind die Prinzessinnen von Oma und Opa. Da merkt man ganz genau, dass die definitiv bevorzugt werden. Es heißt dann immer: ‚Unsere Prinzessinnen.‘ Und bei unserer Tochter heißt es: ‚Die ist ja auch anders.‘“ (I14; l. 423)

Future plans and aims in life totally change. The whole concept of life has to be reconsidered because caring for a multiple disabled child is a huge challenge.

„Man hat ja eine Vorstellung von seiner Familie gehabt oder von seinem Leben oder Träume und Ziele. Als die Diagnose dann gestellt wurde, musste komplett alles neu überdacht werden, neue Ziele gesetzt werden. Es mussten neue Prioritäten geschaffen werden, es wurden alle Pläne geändert.“ (I06; l. 31)

4.5.5 Disabilities' impact on partnerships

Interviewees report different effects on parental partnerships: On the one hand, three parents report negative impacts like drifting apart from each other. Reasons

are described as different coping strategies of partners or overburdening of one partner with the situation. In the end this could lead to separation.

„Man merkte im letzten Jahr, dass eine gewisse Überforderung bei meiner Frau da war. Und mit 40 Jahren kam dann der Dreh: War es das jetzt in meinem Leben? Also Midlife Crisis. Das hat leider unsere Beziehung nicht überstanden.“ (I04; I. 214)

The larger part of parents describes the contrary: The disease brings them closer together as a couple.

„Es hat uns zusammengeschweißt. Wir sind ein eingespieltes Team, er kann sich auf mich verlassen und ich kann mich auf ihn verlassen.“ (I14; I. 440)

It becomes apparent, how important shared time out as couple is for the persistence of an intact relationship. Seven parents report the importance of shared activities and mutual experiences.

„Wenn wir alleine im Urlaub sind, dann sind wir wieder ein Paar. Also auch mit Albernheiten und Allem“ (I01; I. 193)

4.5.6 Disabilities´ impact on siblings

Almost all parents describe the relationship between the disabled child and the siblings as affectionate and close. Siblings are described as highly empathetic and thoughtful.

„Ich sehe eigentlich bei allen Familien, dass die Geschwister eine unglaubliche Bereicherung sind. Sie sind sehr förderlich für die Entwicklung des Rett Kindes und haben alle unheimliche Empathie. Das ist unglaublich, wenn man sieht, wie liebevoll die mit den Geschwistern umgehen.“ (I03; I. 351)

It becomes apparent that siblings also positively affect the development of disabled children because they mostly try to involve them in their daily routine and plays.

However, there are some problematic points mentioned in the interviews.

The first is the risk of neglecting or burdening siblings due to the challenge of the child's disability. Almost half of the parents mention this as a possible problem.

„Auch ein Elterntag hat nur 24 Stunden und wenn ich mit Therapien beschäftigt bin, ist die Zeit für das Geschwisterkind nicht da. Aber da sollte man Lösungen finden und sagen: Einen Tag pro Woche kommt nachmittags jemand von der Lebenshilfe oder AWO und der Tag ist nur für das Geschwisterkind reserviert.“ (I01; I. 357)

In two cases parents report siblings' problems to cope with the situation of having a disabled sister. They cannot understand why their sister is different or treated different by the society.

„Eigentlich kann ihr Bruder es bis heute nicht richtig verarbeiten, dass sie behindert ist. Für ihn ist es zwar normal, er geht auch liebevoll mit ihr um, aber trotzdem merke ich, dass da so eine Traurigkeit und Schwere ist.“ (I11; I. 14)

Most parents have no experiences with negative impacts on siblings. However one group leader describes possible psychological and physical consequences parents report in her group.

„Es gibt viele Suchtprobleme, Alkohol, Drogen, Waschzwang und sonstige Zwänge. Das hört man relativ häufig und ich würde sagen auch überdurchschnittlich häufig. Wir merken wirklich, dass das ein riesengroßes Problem ist.“ (I01; I. 339)

One mother further describes an anxiety disorder her son developed.

„Unser Sohn hatte eine Angstpsychose, der hat sich immer im Schrank versteckt und wollte nicht mehr in die Schule gehen. Das war ganz furchtbar.“ (I05; I. 139)

4.5.7 Disabilities´ impact on friendships

The disabilities´ impact on friendships is quite diverse. In eight cases parents describe that some of their friends could not cope with the new situation and withdraw from them. Reasons are for example unwillingness to accept the situation or problems in planning common leisure activities. Most parents describe such a selection as positive because it makes clear who the real friends are.

„Wir haben viele Freunde, die damit umgehen können. Wenn vorher Freunde da waren, die damit nicht umgehen konnten, dann müssen sie weg bleiben. Man findet immer wieder neue Freunde. Das sind dann auch keine wahren Freunde gewesen.“ (I13; I. 217)

The existing circle of friends is described as a helpful support system which facilitates the parental situation. They offer care-support but also give the affected families a feeling of affiliation and appreciation.

„Wir haben ganz tolle Freunde, die überhaupt keine Berührungängste haben, immer sehr auf uns eingehen und uns auch besuchen.“ (I04; I. 45)

Two parents describe how they build new friendships by the disability because they get to know a lot of new people in the parental initiative who are empathetic and supportive.

„Durch die Elternhilfe sind nette Kontakte mit Menschen entstanden, denen man sonst gar nicht begegnet wäre. Kontakte, die uns unterstützen. Als unsere Tochter im Krankenhaus lag, ging es drunter drüber (...) und da waren dann die Freunde aus dem Verein, die auf der Matte gestanden und angerufen haben: ‚Was können wir helfen?‘.“ (I08; I. 65)

4.5.8 Family & Social Situation in a nutshell

Parents experience the lack of leisure activities and time for social life as a heavy burden. Spontaneous adventures without the child become almost impossible, because appropriate care must be assured. This is linked to high organisational requirements. Joint adventures as family are also hard to organize because some activities are not possible depending on the mobility and health status of the child. The expansion of support times and short-term care could help parents to enhance their involvement in social activities and thereby disburdens them.

The way how society reacts to disabilities is diverse. Stigmatisation, disregard or pities are experienced as burdening, but there is also support and empathy. The way how outsiders gaze at the disabled child is something which is experienced different by parents. Some are not bothered by these stares because they consider it as normal and are willing to openly explain their situation. Others experience them as awkward and disturbing. Parents' reactions depend on their own conditions. Commiserate views are not welcome.

The disability has an impact on the whole family and on friendships. The relationship between the disabled child and her siblings is widely described as close, sibling themselves are highly empathetic. Nevertheless the disabled child is always in the focus of the family which can lead to a neglect of siblings. Most parents are aware of this danger. Problems in coping with the situation can express in siblings in deep sadness, different forms of addiction or obsessive-compulsive disorders.

The way how friends cope with the disability is diverse. There are friends who withdraw from affected families because they could not accept the new situation or restrictions in social activities. Other friends stay or even become closer; these friends are considered an important support system. Some parents also found new friends in the parental initiative, because these friends are in the same situation. They have a good understanding of their problems and needs.

Influences on parental partnerships are split into two groups. One group of parents describe they drift apart due to the new situation. Reasons are different coping strategies or overburdening of one partner. Other couples become closer due to the challenges they had to meet, shared time out and experiences as a couple are important for the persistence of a partnership.

Frequently mentioned are assignment of guilt and reproach especially by family members. These reproaches vary from assignment of guilt for the origin of the disability and disregard of the affected child to accusation of possible abuse. Also the blame of living on exploiting the welfare system was mentioned. Parents can also be confronted with the incomprehension for handing their child into a fulltime-care facility.

A special challenge in dealing with the disability is to accept that the formerly healthy child will lose its speech and most of its skills and motor abilities. This is a shock for parents. Most families had plans of their future with the family. The diagnosis totally changed their lives, plans and aims. Relatives sometimes struggle with the new situation, are not willing to accept the disability or withdraw from affected children and their parents.

4.6 Coping strategies

This chapter summarizes all statements elaborating on parental coping strategies and on problems arising from lacking awareness.

4.6.1 Open minded approach

The majority of parents practice an open-minded handling of the disability. They behave self-confident and take their child with them to public spaces like restaurants but also on holiday without being intimidated by others. They see their child as normal part of the family.

„Ich gehe mit ihr Schwimmen, wir nehmen sie überall mit hin und fahren mit ihr in den Urlaub. Sie gehört zur Familie.“ (I13; I. 85)

The particular behaviour of Rett children sometimes appears inappropriate in public spaces to strangers. Two parents describe the importance of developing a callousness to accept and ignore such particular situations.

„Das Wichtigste ist, sich Dickfelligkeit zuzulegen im Bezug auf die Reaktionen der Umwelt, da die Leute manchmal doch komisch gucken. Dadurch, dass unsere

Tochter nicht sprechen kann, äußert sie sich manchmal ein bisschen lautstärker, wenn sie sich unwohl fühlt und beispielsweise Hunger hat.“ (I15; I. 379)

Two mother who advocates the open-minded approach point out struggles in combining disability-specific behaviour with the predominant social norms.

„Es ist manchmal so, gerade wenn ihre Anfälle kommen, dass man schon so weit in die Gesellschaft involviert ist, dass es in manchem Momenten einfach nicht passt. Das man denkt: ‚Ich muss jetzt schauen, dass ich hier weg komme‘. Aber nicht, weil mir das unangenehm ist, sondern weil ich weiß, da hört die Toleranzschwelle von Anderen auf.“ (I12; I. 94)

One mothers weights the own quality of life which is enhanced by family activities like restaurant visits against the feelings of outsiders.

„Wenn man aus Angst vor Blicken nicht mehr ins Restaurant geht, ist das ja auch schade. (...) Was ist unsere Lebensqualität gegen die Nerven anderer Leute? Es gibt schon Sachen, die machen wir nicht, aber es gibt vieles, was wir auch ausprobieren.“ (I15; I. 727)

The openness in handling the disease seems to be important, but two parents explain that such shared family activities are partially exhaustive for them.

„Wir fahren mit dem Wohnwagen und da ist sie dabei. Es ist für uns alle sehr anstrengend. Also es ist eine große Herausforderung, aber wir wollen das so.“ (I07; I. 213)

It becomes apparent that an open-minded approach has an impact on social constructs and reactions on the disability. One mother summarizes that positive handling of the disability also has also psychological impact: It alleviates the coping process and the acceptance in parents but also helps others in handling the affected child because everybody knows about her situation.

„Der offene Umgang hat ungemein geholfen. Erst mal bei der Verarbeitung, dann bei der Umsetzung und bei der Akzeptanz. (...). Jeder weiß genau, was mit ihr los

ist, warum und weshalb und kann auch dementsprechend mit ihr umgehen.“ (I06; I. 343)

One mother describes that many parents commiserates themselves. This complicates the acceptance of the disability. She advocates for acceptance of the situation without complaining about it.

„Wenn ich das dann immer höre: ‚Mein Kind hat die ganze Nacht nicht durchgeschlafen, guck mal was ich für schwarze Augentränder habe‘. Die wollen sich nur selber bedauern lassen. (...) Ich sehe das nicht so verbissen. Viele sind da, die rumjammern.“ (I13; I. 133)

4.6.2 Avoidance of confrontation

Some parents have problems to be confronted with the disease. Four parents describe contact with other affected families as problematic, because meeting other children with Rett syndrome enhances fears.

„Es gab bei dem Treffen Mädchen, die noch laufen konnten und es gab welche, wo man dachte: ‚Das arme Kind kriecht ja nur auf dem Boden und kann gar nichts.‘ (...). Ich bin so ein Typ, der nah am Wasser gebaut ist und wir sind weg von diesem Treffen und ich habe nur geheult im Auto.“ (I07; I. 276)

Confrontation with other children can show parents quite plainly which impact the disease could have on their own child in the future, but it can also give hope because it can demonstrate positively developing children.

„(Konfrontation) kann auch Hoffnung machen, wenn man sieht, wie sie sich entwickeln können. So ein Treffen gibt immer die Chance Hoffnung aufzubauen, aber auch einige zurückzuwerfen.“ (I02; I. 282)

4.6.3 Societal awareness

Three parents criticize that the awareness level in the society is still low. They claim a better education which could facilitate handling and acceptance of the children with Rett syndrome.

„Die Aufmerksamkeit für Rett ist zu wenig. Die Leute hören: ‚Das ist Rett‘ und dann ist es auch schon wieder vergessen. Es kommt nicht immer in der Masse an.“ (I01; l. 448)

4.6.4 Coping strategies of parents in a nutshell

An open-minded approach is the way most of the interviewees cope with the situation. They see their children as family members and try to involve them as much as possible in shared activities even if this is exhaustive. Certain callousness is important to stand above people's reaction on disability-specific behaviour. Finding a compromise of adequate considerateness towards the interest of others without restricting oneself in quality of life is difficult, but important. This is compliant with the suggestion to make the best out of the situation. Parents still consider public education and awareness as insufficient.

Network with other afflicted parents is usually described as a resource. But some parents tend to avoid contact with other affected children. They experience this confrontation as frightening because it shows them how the progress of the disability could impact their child in the future. Otherwise such confrontation can give hope because it also shows positive courses of the disability.

4.7 Prospects

This chapter summarizes all statements about the fear of releasing the child from parental care and worries about the future.

4.7.1 Release of the child

One big issue is the fear of releasing the child in fulltime-care facilities. Reasons for this are manifold. One problem is the insecurity of parents that care in such facilities is as sufficient and adequate as they offer it at home.

„Man hat sich in ein bestimmtes System eingearbeitet, man hat einen geregelten Ablauf, man weiß, wie es funktioniert und wenn man dann sagen soll: ‚Sie geht jetzt in eine Einrichtung‘, da ist ja dann alles anders und das ist extrem schwierig zu sagen: ‚So ist es für mich auch in Ordnung‘. Und je älter die Eltern, je älter das Kind und je länger das System so gelaufen ist, desto schwieriger wird es.“ (I03; I. 311)

Another mother describes the problem of transferring responsibilities to nursing staff as something which was very hard for her.

„Ich habe ja alles für sie getan und dann ist sie von einem auf den anderen Tag weg und dann machen andere Leute alles und ich habe nicht mehr die Kontrolle. Das war das Schlimmste, dass ich mir gar nicht vorstellen konnte, dass das alles so klappt.“ (I14; I. 592)

Another parent fears nurses could have problems understanding her child due to the lack of communication skills. This could complicate the handling of the child.

„Das Loslassen ist schon ein schwerer Prozess, gerade wenn die Kinder so auf uns angewiesen sind und die Sprache fehlt. Sie können sich halt nicht äußern.“ (I03; I. 317)

The assumption that home care is the only right decision is shared and communicated by another mother.

„Ich sage, dass jeder ein Recht auf ein Zuhause hat. Also sagen wir mal, dass ich irgendwann nicht mehr kann, weil ich zu alt bin, dann muss man drüber nachdenken. Aber wir sehen zu, dass sie zu Hause bleibt.“ (I13; I. 72)

Four parents describe the transition into a fulltime-care facility as best decision for both parents and children. On the one hand the handling of the child becomes more difficult the older it is and so it is hard for parents to cope with the requirements of care, on the other hand such a facility offers support and facilitates the contact to children of the same age. A point of time some parents choose for letting their child go to a care facility is their 18th birthday.

„Wenn sie volljährig wird, wird sie in eine Einrichtung gehen. (...) Denn ich bin nicht in der Lage sie nach der Schulzeit ganztägig zu betreuen. (...) So ein Kind kann man nicht in die Ecke stellen. Die braucht Betreuung und Abwechslung. (...) Der Betreuung, die in einer Einrichtung oder in der Schule gemacht wird, kann man nicht gerecht werden.“ (I04; I. 312)

4.7.2 Future thoughts

A big issue for parents is their fear what will become of their child for the time when they will be dead. They are afraid that the child might be helpless and unsupported.

„Wichtig ist, dass sie ein Leben führen kann, was für sie erfüllt ist. Dass sie sich auch ausdrücken kann, dass sie Freundschaften und Beziehungen knüpfen kann und dass sie nicht hilflos allem ausgeliefert ist. (I15; I. 600)

Two parents hope their children will not survive them so that they can go along with them and support them until they die.

„Das hört sich vielleicht gemein oder böse an, aber ich hoffe, dass sie uns nicht überleben wird und ich im Prinzip bis zum Ende bei ihr sein kann.“ (I12; I. 249)

Two mothers fear of worsening of the child's health condition especially if it has not already overcome the four stages of the disability (see chapter 2.1.1.)

„Es kann ja immer wieder zu Verlusten von bestimmten Fähigkeiten kommen und die letzte Phase fängt demnächst an. Da können gerade die motorischen

Fähigkeiten noch schlechter werden. Und wir haben schon Angst davor, dass sie irgendwann nicht mehr so gut laufen kann.“ (I15; I. 557)

Adverse to that, one parent remarks her hope that there will be a progress relating to therapies and the possibility that the affected child could regain her lost abilities.

„Wir hoffen, dass sich irgendwann bei den Gentherapien etwas tut, dass unsere Tochter vielleicht auch Fähigkeiten mit Therapien zurückgewinnen kann und dass sie vielleicht doch irgendwann mal anfangen kann zu sprechen. (I14; I. 573)

Three parents displace fears of the future to better cope with the situation. They only focus on the present situation without worrying about future problems.

„Sich jetzt schon einen Berg von Problemen schaffen, die noch nicht aktuell sind, das macht es einem unnötig schwer. Deshalb machen wir das Schritt für Schritt. In dem Moment, wenn es soweit ist, werden wir uns damit beschäftigen. Es ist zwar immer im Hinterkopf, aber ich denke, man muss auch vieles ausblenden und den Tag und die Situation genießen.“ (I06; I. 317)

4.7.3 Parents' prospects in a nutshell

A problem experienced by many parents is fear to release their child into a fulltime-care-facility. Some parents cannot imagine to hand their care-responsibilities over to someone else. Reasons are unwillingness to loose control but also the unimaginably that someone else could offer such a good standard of care as parents do. There is the fear that children could not show their wishes and desires due to insufficient communication skills. For some parents it is hard to accept that the care cannot be equal to home-care.

When the affected children finished school they are depending on full-time parental care. A couple of parents admit that this challenge is hardly affordable for them at home because the older the children get the more meaningful occupation they need. This is why the bulk of parents are aware of a fulltime-care facility as the best solution for both sides.

Some parents experience fears of the future. Frequently mentioned is the fear to die before the child. This would mean to leave the child alone and potentially helpless. This is why most parents considered preparing their child for the future and for a life outside the family. Other parents hope that they could accompany their child until they die.

Worsening of the child's health conditions is another fear that burdens parents. Some hope for medical progress and the development of new therapies or even cure.

In other cases parents cope best by ignoring future fears. They make the best out of their present lives and their situations and enjoy shared time with their children without worrying about the future.

4.8 Summary of Results

This study has identified potential burdens and needs in the areas of *everyday-life, formal support and strains, financial situation, personal health, social and familial support and strains, coping strategies and prospects.*

For the category everyday-life, 6 subcategories were identified (*care as challenge, communication as challenge, mobility as challenge, accessibility of care, structural circumstances, and potential relief*). It becomes apparent that caring for a child with Rett syndrome affects parents' everyday-life in different ways: The care of affected children is time consuming and exhaustive and also linked to the mobility status of the child because the higher the restrictions in mobility the more support by parents is required. Sleeping disturbances, screaming phases, perceptual disturbances and epileptic seizures are symptoms which burdens parents and also restrict shared family activities. Organizing the daily routine is hard because all transactions are depending on the child's health condition. Some parents feel helpless and wish for support in structuring their daily tasks. The introduction of an emergency-number was mentioned as possible idea for relief. Problems in communication are common because speech abilities are mostly very restricted. There are local differences in the availability of medical support for affected children. Especially rural and suburban areas have an undersupply of specialized doctors. Parents of children reliant on wheelchairs criticize the lack of handicapped accessible constructions in public institutions and places. Emotional and care

support are important for parents to cope with these high burdens of care in everyday-life. Partners and families are described as internal support networks while family-support services and short-term care services are described as helpful external support systems. Some parents prefer assistance in care at home by babysitters or nannies. The possibility of claiming such services is depending on allocation of care levels and thereby on availability of care allowances. Parents also experience relief by bundling of different therapies in schools, information exchange and support by parental initiatives and the practice of Kinaesthetic. Supported communication improves the communication with affected children and alleviates mutual understanding.

The study also identified deficiencies in the area of formal support. 8 subcategories were identified (*late diagnosis, disease specific knowledge, health professionals behaviour, short-term care and fulltime-care facilities, nursing staff, allocation of care levels, benefits by health insurances, school situation*) Late diagnosis is a frequently mentioned problem. The multitude of examinations and uncertainties about the appropriate diagnosis are burdening so that the diagnosis in the end is experienced as relieving. Disease-specific information and information about legal rights, reimbursements and contact points are rated as insufficient. While some parents are dissatisfied with disease-specific knowledge of medical staff others noticed an increase in knowledge. The transfer of information as well as the support after diagnosis is considered as insufficient which leads to a feeling of helplessness in many parents. Due to that most parents search for appropriate information on their own but wish for support by coordination centres or disability representatives. The behaviour of health professionals is described as rude and less empathetic. Parents feel less supported by them. Formal support by short-term care services and fulltime-care facilities is criticised with regard to lacking availability, long waiting lists and an insufficient patient-nurse-ratio. One mother remarks her doubts due to abuse. Nursing care services are criticised for fluctuation of nursing staff because Rett-girls are dependent on consistency. Also the caring-approach which strongly focuses on high-maintenance care of elderly people is considered as inappropriate for the needs of Rett-children. A better education not only disease-specific but also on emotional level is desired. The American example of specialised Rett-nurses responsible for care but also for support in other disease-specific belongings is

mentioned in this respect. The scope of service by health insurances is largely considered as too limited. Reimbursements which exceed standards are oftentimes not approved or they need formal objection. Highlighted is the hippo therapy as most helpful therapy in reducing or preventing scoliosis which is not covered by the scope of service while other expensive therapies with similar results are covered. Appropriate allocation of care levels by the medical review board of the statutory health insurance funds are also mentioned as a problem in formal support.

Parents are mostly satisfied with the school situation. Lacking education with regard to supported communication and the unwillingness of teachers to develop support plans for the children were mentioned as burdens. In some cases school supervisors are used to support teachers rather than supporting the affected child. In the area of financial situation 3 subcategories were identified (*labour situation, care allowance for parental nursing care, additional costs*). The disability affects financial situations of families due to the common shortfall of one income (due to high care requirements) and additional disease-related costs. This reduction or job leaving mostly affects women because they are caregivers for the children in most instances. If families experience this shortfall as burdening is largely depending on the partners' income. Some caregivers are still working because they consider this employment as compensation for care-requirements at home. Additional costs can also burden families, especially structural alterations at home or special equipment for childcare. The insufficient payment of care allowance for parental nursing care is criticised because caring for a child with multiple severe disabilities is highly challenging and therefore compensation not adequate.

The disability can impact the parental health status. 3 subcategories were identified (*time for recreation, physical situation, psychological situation*). High care requirements can lead to a lack of time for recreation which results in resignation or frustration. Most parents are aware that taking time for recreation is important to recharge power. Every parent still has an own life which should not only centre on child care but also on own needs. Depending on the child's mobility care can negatively impact the musculoskeletal system because it is linked to carrying and lifting activities. Dependent on the child's weight this can be challenging. But also mental effects like depression, the feeling of exhaustion and sleeping disturbances are mentioned. The demand of psychological support especially during the period

of diagnosis becomes apparent. One mother gave the example of considering the family as system as her psychologist did and which she considered as helpful.

7 subcategories were identified in the area of social support and strains (*leisure/ social life, societal acceptance of the disability, guilt and reproach, familial acceptance of the disability, impact on partnerships, impact on friendships, and impact on siblings*). In the society, disabilities are still considered as a blemish. Some parents feel burdened by stares of outsiders. One parent adds that commiseration is not welcome. Parents experience social strains in terms of lacking time of social activities and leisure time. The wish to extend these times becomes apparent. Most parents try to establish own free spaces because they need it to recover from disability-related stress. However this is linked to high organisational challenges. Due to this, parents desire an extension of respite care times as relief.

Reproach and assignment of guilt are widely spread. Reproaching for the disability by family members, the reproach of neglect or abuse but also families' blame for living on welfare is common. One parent was reproached for handing her child over in a fulltime-care facility. To accept the disability was hard for almost all parents because they act on the assumption that their child is healthy. To accept that the child will lose all its motor skills and speech is a shock. Future plans and aims totally change. Relatives sometimes have problems to accept the disability or favour other children in the family who have no disabilities.

Relationships with friends and partners can be affected positive or negative: It can bring people closer together as friends or as couples or make them split up. This is depending on how the opposite side can cope with the burden of disease and the new situation. The withdrawal of friends is widely described as positive because it "separates the wheat from the chaff". Friends who stay are considered as important support system. Some parents found new friends in parental initiatives because they share disability-related experiences.

Siblings are described as highly empathetic and affectionate in exposure to their affected sisters. Fear to neglect siblings is present but most parents are aware of this danger and try to avoid it by reserving time only for the sibling. Sorrow, addictions and obsessive-compulsive disorders are prevalent problems in siblings. One mother describes the anxiety disorder of her son.

In the area of coping strategies 3 subcategories were identified (*open-minded-approach, avoidance of confrontation, level of awareness*). Parents use different coping strategies to handle the disability. Most of them are open and self-confident in exposure to the disability and maintain to do share activities as a family. They also mention the importance to get callousness to cope with the situation. Although these shared activities can be exhaustive families want everyone to see the child as normal part of their family.

Taking the child into public spaces like restaurants or cinemas can be afflicted with problems. Most parents respect social norms and feelings of other people without restricting their own quality of life too much. Therefore shared family activities are always a challenge. The open-minded approach helps to cope with the disability and makes the handling of the disabled child easier for outsiders: They know how to react on disease-specific behaviour. Some parents avoid contact with other affected children because these meetings increase their future-fears. On the other hand such meetings can give hope because positive courses of disease can be identified.

An increase in social awareness is desired to make the exposure easier for parents. Awareness can raise acceptance for the disability and disburdens the exposure for parents, affected children and the society.

Future prospects are also an issue. 2 subcategories were identified in this area (*release, future thoughts*). Many parents hesitate to hand their children over to a full-time care facility. To release the child from parental care in strangers' hands is hard to accept because parents mostly adopted care for many years and know best what the child needs. Since the children lack basic communication skills this aspect is vital for their quality of life. Fear of loosing control, the lacking communication skills of the child or the belief that such a facility could not offer appropriate care are reasons for unwillingness to let children go. Fears of the future also exist, especially the fear of dying previous to the child. This increases the fear of leaving the child helpless and unassisted. Some parents hope they could accompany their children until they die. One parent mentioned the fear of disabilities' progress and loss of abilities and motor skills. Others simply ignore future fears. They enjoy shared times as family and only focus on current problems. A big wish is to prepare the child for the future so that she is able to make friends, to live as independent as possible, happy and without the feeling of

helplessness. One mother still hopes in medical progress so that the disability can be cured one day.

5 Discussion

5.1 Interpretation of Results

To be the caregiver of a multiple severely handicapped children is a high burden because it is linked to varied challenges: Mental and physical burdens, extreme stressful behaviour of the child (e.g. screaming phases, epileptic seizures, sleeping disturbances) and external factors (e.g. lacking social or formal support) lead to extraordinary burdens for parents of such children.

Most results of this study already emerged in current international scientific literature which was reviewed in advance. However some findings could not be confirmed by this study: Previous studies showed that most parents feel financially heavily restricted and described that half of them slide towards poverty because of additional costs due to the disability (Kuhltau et al 2005; Anderson et al 2007; Sloper & Beresford 2006). In this study, most parents indeed describe a reduced overall income due to the disability but rate it as sufficient anyway. Also the statement that most families with disabled children are one-parent-families (Anderson et al 2007) could not be affirmed. In this study only two parents are divorced. One of these parents already has a new husband. The finding that loneliness is experienced by parents in large parts (Ray 2006; Sen & Yurtsever 2006) could also not be proved. Most parents in this study describe their social network as sufficient, social isolation was not mentioned. Another departure from literature is the dissatisfaction with school situations (Murphy et al 2007; MacDonald & Callery 2008; Anderson et al 2007; Bourke Taylor et al 2012) especially with regard to teachers' education (Lutenbacher et al 2005). Parents in this study are mostly satisfied with schools and teachers. The only criticism was on lacking education of teachers with regard to supported communication. The differences may occur due to selection bias via the self-help-group. Other reasons for deviations from international literature may be the German welfare state and system of family support as well as the high standard of technical support available for parents.

Comparing information of the parental Rett initiative¹³ with problems parents mentioned in the study show many similarities. The initiative offers disease-specific information including symptoms, diagnosis and therapies. Possible therapies and supported communication are introduced and provided with links for further information. Strategies and ideas for coping with everyday-challenges are proposed and illustrated with field reports. For questions of rights and benefits, the Rett initiative offers a free hotline for “disability rights”. Referring to diagnostics the blood test is further described and conducting clinics are mentioned. A medical advisor is named for support in medical questions. Also specified clinics, contact persons and helpful links are listed on the homepage. Summing up the parental initiative offers a sufficient spectre of disease-specific information and support.

Results of this study largely confirm results of previous studies focussing on the situation of parents with disabled children in general. However there are some disease-specific characteristics, which were not discovered in previous research: The fact that parents give birth to an obviously healthy child .which will become severely and multiply handicapped over the years is a real shock. To accept this is hard and afflicted with deep sorrow and anxiety. Some parents even “fall into a deep dark hole”. This is why in this context the importance of psychological support after diagnosis is highlighted but in reality almost non-existent.

Another disease-specific challenge is the limited ability for communication which handicaps the understanding between parents and children. This lacking communication burdens parents a lot because they cannot react on the child’s desires and have no clue to which extend their child understands them. This may be one reason for the described unwillingness and fear of parents to release their children into care facilities. They rather accept the overburdening of fulltime-care at home than permitting to leave their child helpless without their support and care. The introduction of specialised nursing services which employ staff with disease-specific knowledge could facilitate this situation and enhance parental trust in medical staff. Furthermore the bundling of medical support, therapies and other disease-specific facilities in centres could be helpful because it safes time and effort. Such an effect could also be achieved by the introduction of a Rett-specific Rett-syndrome-representative as counterpart for a commissioner of foreigners who

¹³ www.rett.de

already exists. These services could serve as contact points for affected parents. The scope of service of health insurances should be adjusted to the needs of parents caring for disabled children. Actually they follow strict rules without considering specific needs. A disease-specific focus can reduce costs in long-term view (e.g. inclusion of hippo-therapy into scope of service can reduce cases of scoliosis and thereby decrease high costs of scoliosis operations which are covered by health insurances.)

The previous qualitative study outlines the life situation of parents caring for children with Rett syndrome and highlights the afflicted burdens and needs. Areas with need for improvement could be identified. Support in these areas could disburden parents and thereby increase their quality of life.

5.2 Weaknesses and limitations

This study shows some weaknesses: The sample exclusively consists of members of parental initiatives (affected parents and group leaders). It can be assumed that parents who are organized in such an initiative are generally more motivated and dedicated than parents who are not members in such an organisation. Also the fact that most interviewees use an open-minded approach to cope with the situation may be due to a selection bias because other parents are probably not powerful enough to organize in such an initiative. Thereby only one specific group of affected parents is represented. Furthermore it becomes clear that the group of immigrant are not represented. All interviewees who agreed to participate in this study are of German origin. This is why possible specific burdens and needs of ethnic subgroups could not be outlined in the context of this study. It was possible to include working class parents, though. However, most participants are well-off. Another critique is that the interviews were conducted by telephone. Most interviewees were communicative and willing to answer questions. However personal contact might intensify mutual trust between interviewee and researcher and allow more in-depth conversations. For this purpose such a study should be extended and sponsored to make travelling to interviewees' homes possible by cost-recovery.

The Rett syndrome is a disability with diverse characteristics and severities. Because of this it is hard to compare disability-specific needs of children in

different age groups and different mobility status. The interviewees' children are all of different ages, in different stages of the disability and have different severity indexes. Thereby some may have completely different abilities and skills than others. Also the differences in mobility have a high impact on the differences in care and support requirements: some children are totally agile while others are dependent on wheelchairs. The burden increases and decreases with the severity of the disability. Another factor which may distort the results is the responsibility of care. While many parents care for their child at home, others already handed them into fulltime-care facilities (e.g. one mother gave her daughter in a fulltime-care facility in the age of 6). Thereby the care requirements and challenges differ and situation of these parents are hard to compare.

With respect to diagnostics but also to the state of knowledge of health professionals the study does not implicitly represent the current situation. Parents taking part in this study mostly got the diagnosis many years ago (some of the children are 25 years by now). Diagnostics took longer than today because the blood test which is available now was not developed until 1999. Education and support by health professionals may also have changed in the meantime. For further analysis a study with parents of freshly diagnosed children would be helpful.

5.3 Expectations

This study gives an overview about the situation of parents caring for children with Rett syndrome. They are exposed to higher burdens and needs compared to parents of healthy children and with burdens that differ, sometimes decisively, from caregivers of children with other disabilities. There are many areas of care in which improvements are needed to enhance their life situation and to guarantee optimal care for affected children. An improved integration of stakeholders in the public health sector could considerably ameliorate the situation. Furthermore the transfer of sufficient information and education in a more sensitive way should be aspired. This could in the end diminish the psychological strain which results from lacking acceptance and awareness in society.

To make generalisations of findings in this study further research is needed. A quantitative study is imaginable which should be conducted with randomly

selected cases nationwide under consideration of disability-specific influencing factors. This qualitative study could serve as a basis for the development of items. The challenge of such a study is the accessibility of parents who are not organized in a parental initiative.

In the end an intensive examination of the burdens and needs of parents who have children with Rett syndrome can lead to an increase in their quality of life, but also positively affects the health system: High stress levels which are due to high requirements of care can possibly lead to burn-out, depression or severe physical harms, leading to additional costs for treatment. Calling attention and thereby diminishing burdens and needs of affected parents can decrease this risk of additional costs for the health system in long term.

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Statutory Declaration

I declare that I have authored this thesis independently, that I have not used other than the declared sources/ resources, and that I have explicitly marked all material which has been quoted either literally or by content from the used sources.

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Date

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Name

Appendices

Appendix 1: Interview guideline

Appendix 2: Covering letter for parental initiative leaders

Appendix 3: Example for summarizing content analysis

Interviewleitfaden für betroffene Eltern

Wichtig: „Ist es für Sie in Ordnung, dass ich das Interview aufnehme?“

Einstiegsfragen: Alltag mit einem Rett Mädchen

- *Wie empfinden Sie den Alltag/ das tägliche Leben mit ihrem Kind? Erzählen Sie doch mal, wie ein typischer Tag bei Ihnen aussieht.*
- *In wieweit hat sich durch Ihr Kind ihr eigenes Leben verändert?*
- *Gibt es Situationen im Alltag, die Sie als besonders belastend oder problematisch empfinden? Falls ja: bitte spezifizieren lassen*

Ich würde jetzt gerne etwas mehr auf spezielle Aspekte eingehen. Bei meinen Recherchen ist mir aufgefallen, dass Eltern chronisch kranker und behinderter Kinder häufig mit besonderen Herausforderungen konfrontiert sind. Hier würde ich gerne auch bei Ihnen mal nachhaken.

Finanzen

- *Hat die Erkrankung Ihres Kindes finanzielle Probleme mit sich gebracht?*
 - *Arbeitszeitverkürzung/ Aufgabe Job*
 - *Kostenübernahme /Zuzahlungen (Krankenkassen, Sozialamt etc)*
 - *Wie werden mögliche finanzielle Engpässe überbrückt?*

Externe Unterstützung

- *Erinnern Sie sich doch mal zurück an die Zeit der Diagnosestellung: wie gut haben Sie sich damals beraten und betreut gefühlt und wie ist es heute mit der Unterstützung?*
- *Wer hat Sie beim Finden von Hilfen/Experten/ Informationen unterstützt?*
- *Wie wirkt das Hilfesystem in die Familie hinein? Wie empfinden Sie die Zugänge zum Hilfesystem? Welche Möglichkeiten, welche Hürden und Grenzen gibt es? (Entfernung/Transport; Unterstützung durch Ämter, Familie, Krankenkassen, Spezialisten)*

- *In welchen Bereichen der Versorgung würden Sie sich mehr Hilfe/Verbesserungen wünschen?*

Eigene Gesundheit

- *Haben Sie das Gefühl, dass die Versorgung ihres Kindes auch Auswirkungen auf Ihren Gesundheitszustand (psychische Belastung/ somatische Beschwerden) hat?*
- *Spielen Sorgen und Ängste (auch im Bezug auf die Zukunft) in Ihrem Leben eine Rolle?*

Sozialleben und Beziehung und Familie

- *In wieweit haben Außenstehende Verständnis für ihre Situation?*
 - *Konfrontation mit Stigmatisierung*
 - *Vorwürfe*
 - *Wissen über die Erkrankung*
- *Fühlen Sie sich von Freunden und Familie genügend unterstützt?*
 - *wie sieht diese Unterstützung aus?*
- *Wie empfinden Sie die Auswirkung der Erkrankung Ihres Kindes auf*
 - *bestehende Freundschaften/ soziale Kontakte*
 - *die partnerschaftliche Beziehung*
 - *aufs Familienleben insgesamt (Geschwister, Grosseltern, gemeinsame Aktivitäten)*
 - *Wie gehen sie mit diesen möglichen Auswirkungen um?*

Abschluss

- *Gibt es noch etwas, das Ihnen wichtig ist?*
- *Was würden Sie sich wünschen, um die Situation von betroffenen Eltern zu verbessern?*

Soziodemografie

- *Anzahl der Kinder*
- *Alter des erkrankten Kindes*
- *Wohnort*

Sehr geehrte/r Frau/Herr.....,

mein Name ist Nina Steinhagen, und ich studiere Gesundheitswissenschaften an der Hochschule für Angewandte Wissenschaften in Hamburg. Ich beschäftige mich im Rahmen meiner Masterarbeit mit der Lebens- und Versorgungssituation von Eltern, deren Kind am Rett-Syndrom leidet.

Bereits im letzten Jahr habe ich mich während eines Forschungspraktikums am Institut für Medizinische Soziologie, Sozialmedizin und Gesundheitsökonomie am Universitätskrankenhaus Hamburg Eppendorf im Rahmen einer gemeinsamen Studie mit dem Kindernetzwerk e.V. mit der Lebens- und Belastungssituation von Eltern chronisch kranker und behinderter Kinder beschäftigt. Informationen zum Institut sowie zur Studie können Sie u.g. Links entnehmen.

<http://www.uke.de/institute/medizin-soziologie/index.php>

http://www.uke.de/institute/medizin-soziologie/index_84321.php

In meiner Masterarbeit möchte ich mich nun dem Thema „Rett“ intensiver zuwenden. Die Belastungssituation der Eltern von Kindern mit Rett-Syndrom hat bislang in der Forschung kaum Beachtung gefunden, daher denke ich, dass diese Studie ein guter Ansatz ist, um den Fokus auf die alltäglichen Herausforderungen zu legen, denen betroffene Eltern ausgesetzt sind. Um die Situation der Eltern erfassen zu können, möchte ich gerne mit diesen vertiefende Interviews führen.

Hiermit wollte ich bei Ihnen nachfragen, ob Sie sich als Gruppensprecher/in bereit erklären würden, diese Mail an den Verteiler Ihrer Elternselbsthilfe weiterzuleiten und mir dadurch bei der Suche nach möglichen Eltern von Kindern mit Rett-Syndrom behilflich sein könnten die bereit wären, mit mir ein ca. einstündiges Interview am Telefon zu führen.

Selbstverständlich werden die Informationen anonym behandelt und der Datenschutz eingehalten werden.

Für Fragen stehe ich Ihnen auch jederzeit zur Verfügung.

Ich wäre Ihnen sehr dankbar für Ihre Mitarbeit und verbleibe mit freundlichen Grüßen

Nina Steinhagen, BSc

Fall	Paraphrase	Generalisierung	Reduktion
I04	<ul style="list-style-type: none"> • Geschwisterkind kümmert sich liebevoll • Liebe zwischen Geschwistern ist sehr groß • Es gibt keine Eifersucht • Bruder kümmert sich gut 	<ul style="list-style-type: none"> • Gute Geschwisterbeziehung 	<p>Einfluss auf die Geschwister</p> <ul style="list-style-type: none"> • Enge Bindung • Gute Beziehung
	<ul style="list-style-type: none"> • Eingeschränkte Freizeitmöglichkeiten • Zeitlich stark eingeschränkt • Hoher Zeitaufwand durch Therapien, Arztbesuche etc. sehr belastend • Wunsch nach mehr Freizeitgestaltung für Eltern • Wunsch, dass Eltern mehr Freiheiten bekommen • Wunsch nach Erweiterung der Verhinderungspflege, um selbst mehr Freizeit zu haben • Wunsch nach Personal, damit man auch mal ein zwei Nachmittage in der Woche zum Luftholen hat • Wunsch nach Zeit für sich selbst • Wenig Freizeit kostet Nerven • Wunsch nach Freizeitgewährung um den Eltern ein bisschen die Last abzunehmen. • Es ist auch für eine Ehe wichtig gemeinsam Zeit verbringen zu können, ohne auf die Uhr zu schauen. 	<ul style="list-style-type: none"> • Wenig Freizeitmöglichkeiten • Zeitliche Einschränkungen • Hoher Zeitaufwand durch: Therapien und Arztbesuche • Wunsch nach mehr Freizeit • Wunsch nach Unterstützung/Entlastung • Freizeit= Entlastung • Zeit für Erholung • Gemeinsame Zeit ist wichtig für die Ehe 	<p>Eingeschränkte Freizeit</p> <ul style="list-style-type: none"> • Hoher Zeitaufwand durch Behinderung • Wunsch nach Unterstützung → Schaffung von Freiräumen/Entlastung • Erweiterung von Pflegeleistungen als Entlastung <p>Einfluss auf die Partnerschaft</p> <ul style="list-style-type: none"> • Gemeinsame Zeiten sind wichtig für Bestand • Trennung • Frau war mit Situation überfordert
	<ul style="list-style-type: none"> • Freunde haben keine Berührungsängste 	<ul style="list-style-type: none"> • Freundeskreis blieb bestehen • Keine Probleme 	<p>Einfluss auf Freundschaften</p> <ul style="list-style-type: none"> • Kein negativer Einfluss

	<ul style="list-style-type: none"> • Kommen Familie besuchen • Situation sehr unkompliziert 		<ul style="list-style-type: none"> • Freundeskreis blieb bestehen
	<ul style="list-style-type: none"> • Versorgung auf dem Lande als Problem • Weite Entfernungen zu Therapien/Ärzten • Meist 15 bis 20km entfernt • Wohnt auf dem Lande und deshalb weite Entfernungen • Schlechte medizinische Versorgung auf den Land • Für spezielle Erkrankungen muss man suchen 	<ul style="list-style-type: none"> • Versorgung auf dem Land schlecht • Entfernungen sind weit • Gerade für behinderte Kinder ist die Versorgung schlecht 	<p>Erreichbarkeit von Versorgung</p> <ul style="list-style-type: none"> • Regionale Unterschiede • Auf dem Land weite Entfernungen→schlechte Versorgung für behinderte Kinder
	<ul style="list-style-type: none"> • Ärztliche Betreuung bei Diagnosestellung nicht ausreichend • Arzt hat sich unangemessen verhalten/keine Empathie • Musste sich selbst Informationen beschaffen 	<ul style="list-style-type: none"> • Unzufrieden mit ärztlicher Unterstützung bei Diagnose • Zeit der Diagnosefindung war schlimm • Unzufrieden mit Verhalten vom Arzt • Mangel an Empathie • Informationen nicht ausreichend→eigene Suche 	<p>Verhalten von medizinischem Personal</p> <ul style="list-style-type: none"> • Betreuung bei Diagnosestellung schlecht • Arzt wenig empathisch <p>Informationen</p> <ul style="list-style-type: none"> • Nicht ausreichend • Mussten selbst beschafft werden
	<ul style="list-style-type: none"> • Elternhilfe sehr Hilfreich • Informationsmaterial sehr hilfreich 	<ul style="list-style-type: none"> • Elternhilfe und deren Infos sehr hilfreich 	<p>Elternhilfe als Entlastung</p> <ul style="list-style-type: none"> • Infos waren hilfreich
	<ul style="list-style-type: none"> • Psychisch waren die ersten ein/zwei Jahre schlimm • Sorgen und Gedanken über die Zukunft • Wie geht es später weiter • Umstellung kostet Nerven • Anzunehmen, dass das vormals gesunde Kind behindert ist, ist schwer 	<ul style="list-style-type: none"> • Psychische Belastung in den ersten Jahren • Zukunftsängste • Akzeptanz der Erkrankung schwer • Kind war gesund, jetzt schwerbehindert →hart zu 	<p>Psychische Situation</p> <ul style="list-style-type: none"> • Sehr belastend in den ersten Jahren <p>Akzeptanz der Erkrankung</p> <ul style="list-style-type: none"> • Große Herausforderung • Kind erst gesund→plötzlich schwerbehindert • Hart zu akzeptieren und verarbeiten

	<ul style="list-style-type: none"> • Das muss erst mal verarbeitet werden • Konnte anfangs essen und krabbeln, aber jetzt nichts mehr (Stand eines Neugeborenen) • Kaum motorische Fähigkeiten 	<p>akzeptieren</p> <ul style="list-style-type: none"> • Verarbeitung war schwer • Kind auf Stand eines Neugeborenen 	<ul style="list-style-type: none"> • Kind hat alle Fähigkeiten verloren → Stand eines Neugeborenen <p>Zukunftsängste</p> <ul style="list-style-type: none"> • Wie wird es weitergehen
	<ul style="list-style-type: none"> • Partnerin hat sich getrennt • Erkrankung hatte negative Auswirkungen auf Beziehung • Lebt seit letztem Jahr getrennt • Frau war als Hauptpflegerin mit der Situation überfordert • Frau hat vom Leben noch mehr erwartet • Beziehung hat das nicht überstanden • Vorher alles intakt, hatte nicht damit gerechnet 	<ul style="list-style-type: none"> • Trennung • Frau konnte Situation nicht verarbeiten • War mit der Situation überfordert 	s.o. Einfluss auf Partnerschaft
	<ul style="list-style-type: none"> • Es wird mal geguckt, aber empfindet es nicht als unangenehm oder unangemessen 	Blicke von Außen nicht als Unangenehm	<p>Gesellschaftliche Akzeptanz</p> <ul style="list-style-type: none"> • Blicke werden nicht als unangenehm empfunden
	<ul style="list-style-type: none"> • Kaum bauliche Veränderungen nötig • ein Treppenlift (da Rollifahrerin) • Bau von Rampe • Alles aber noch im Rahmen 	Treppenlift und Bau von Rampe nötig → aber ok	<p>Bauliche Maßnahmen</p> <ul style="list-style-type: none"> • Im Rahmen • Rampe und Treppenlift nötig