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The Final thesis

Parents with Mental Health Disorders and Children Health

Children of mentally ill parents

Pia Neumeier, Year VI, 3 group

Institute of Clinical Medicine, Clinic of Psychiatry, Vilnius University

Supervisor:

Prof. dr. Sigita Lesinskiene

The Head of Department/Clinic:

Prof. dr. Sigita Lesinskiene

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pia.neumeier@mf.stud.vu.lt

SUMMARY

Mentally ill parents and their children's health is an important field of psychiatry. Children of parents with a mental illness are at a greater risk to become mentally ill themselves compared to children of mentally healthy parents. This increased risk is based on environmental and genetic factors, which usually coincide. The risk also varies depending on the parent's diagnosis and the family's social status. Most affected are single parent households.

Interventions in the form of preventive or therapeutic care are available and are proven to successfully improve the parent's and children's health.

Different intervention techniques exist, of which some are focused on the child to strengthen their resilience and helping coping to decrease their risk of developing a psychiatric disorder themselves. Other methods are for the entire family, also aiming to improve the parent's health. Recruiting families to join these intervention programs is difficult. Stigmatisation, shame and fear are some of the major factors preventing help-seeking and resulting in the concealing of the situation by the families.

The German intervention system is not nationwide standardized. Different projects offer help to families with mental illnesses. Some of these projects are local whereas others have offices across the country. Some examples of projects introduced below are "Frühe Hilfen", "chimps", "Netz und Boden", a federal working group or "Auryn". In this Thesis the German system, the situation of parents with mental illness and mainly children's health is discussed with a German psychotherapist. This allows us to get an inside point of view from a professional concerning the health of children living with mentally ill parents and the German intervention system.

KEYWORDS

Children of mentally ill parents, incidence of mental illness, relevance of mental illness for offspring, parents with mental illnesses, children's health, Interventions, Prevention, Therapy, Interventions for children of mentally ill parents, German intervention system for children of mentally ill parents, German healthcare for mental illness

LITERATURE SEARCH STRATEGY

Firstly, finding information about parents with a mental illness incidence and consequences for children's health articles on the platforms Pubmed or Frontiers and psychiatry- and medicine

journals. Evaluating the articles for their information concerning the general information for the introduction and intervention systems. The information about the German system required a separate search in German journals and the individual program webpages. Furthermore, for the German system, leaflets and information from local psychiatric hospitals and the psychotherapist interviewed were gathered. The collected material needed searching to retrieve important and new information to conduct a central theme.

INTRODUCTION

Psychiatric diseases are not rare. It is believed that in German society about 30% of adults are struggling with mental illnesses during their lifetime (1). It is also known that adults with a mental illness are just as likely to have children (1), resulting in approximately 22- 25% of children living with at least one mentally ill parent (2,3). These figures coincide with a study from 2017 showing the worldwide prevalence of children living with mentally ill parents or at least one mentally ill parent being between 15 and 23% (4). Several factors brought together show that children of mentally ill parents have an increased risk of developing psychopathologies themselves. Their risk of developing mental illnesses severe enough to require treatment are three to five times higher than in children of mentally healthy parents (3). Studies have found that the negative impact on a child is greater when the parent has multiple psychiatric disorders or personality disorders, compared to those with one disorder diagnosed (5). Besides having a higher risk of developing a mental illness, these children often show lower social and emotional competence as well as lower academic achievements (3,6,7).

Mental illness and substance abuse are sometimes found to be combined as one in reports or differentiated as separate psychiatric disorders with different outcomes and consequences. Alcohol and substance abuse disorders and children of addictive parents will not be discussed here.

The increased risk of a psychiatric disorder in children of mentally ill parents is due to an inherited genetic vulnerability on the one hand and environmental factors on the other hand (1,8–10).

Twin, adoption and family studies show that genetics is a relevant factor for the occurrence of psychiatric disorders (1). One study compares offspring of mentally ill parents living in foster families with mentally healthy adults and offspring of mentally healthy parents living in families with a mentally ill adult. The results show that the risk of a mental illness is twice as

high for the first scenario and not as much but still increased for the second scenario. This is showing the importance of both factors, genetic and environmental (1).

In most cases it is a combination of both factors, genetics and environmental, rather than one excluded from the other (10).

The risk for the children is further increased if both parents are suffering from the mental illness compared to one parent being healthy (10). This again is not simply due to an increased genetic risk but environmental factors that change accordingly.

The importance of the genetic factor also depends on the mental illness in question.

Anxiety disorders have a large familial aggregation, with an increased risk of four to six times in first degree relatives (11). Twin studies including more than 21.000 individuals investigated the genetic factor in major depression and showed a 37% heritability, although the liability of major depression is believed to be even greater than this point estimate. Adoption studies confirmed their results, although not all adoption studies met the inclusion criteria (12).

In twin-, adoption- and family studies concerning schizophrenia findings showed that the lifetime risk of developing the disease in the general population is 1%. The studies further found that the risk is ten times higher for children of one affected parent and up to 40% if both parents are schizophrenic (10).

Another highly heritable mental illness is bipolar disorders, which has a genetic overlap with other psychiatric disorders, like schizophrenia and major depression. A recent study found that “Individual GWAS markers appear to confer little risk, but common variants together account for about 25% of the heritability of BD” (13). Although some genes have been identified, much of the genetic component to psychiatric disorders is not yet fully discovered (14).

It is common for children to develop the same disorder as their parent, but it is not necessarily like that (2). Some disorders, like Autism spectrum disorder and Schizophrenia or bipolar disorders and major depression for example, even show a genetic overlap (13,15).

In conclusion this shows that genetics are an important component, a person’s genes are not however the sole cause for a psychiatric disorder but merely a sign of vulnerability towards them (8).

A picture used to describe this relationship between genetics and environmental factors, is that of a boat in the sea. Boats are different shapes and sizes. The boat’s structure may be seen as the genetic predisposition a person has for a mental disorder. Whether the boat floats, rather than sinks or gets stuck, depends very much on the sea and the surroundings too and not simply on the boat’s shape, although the risk changes depending on the shape.

This metaphor shows that environmental factors are equally important. Environmental factors include the parent-child relationship, the family situation and social environment. The parent-child relationship is very important and varies greatly depending on both the child's age and the parent's diagnosis. In general however, a mentally ill parent often shows impaired parenting skills, reduced quality of care and disturbed child-parent interaction (16,17). Parents with mental illness commonly provide less reliability for their children and are less dependable than mentally-well parents. As mentioned, the parents' diagnosis is an important factor for the parent-child relationship as well. This is because different psychiatric disorders result in different changes of behaviour or abilities to care for the child. During infancy the neglect by the parent has immense impact on the child's development of cognitive and emotional skills (8). But also older children suffer from the lack of emotional support (3,8). Depression for example reduces the parents emotional availability, maternal involvement and response and affects the child differently depending on its age (10,18). A study (19) was performed to investigate postpartum depressions and the consequences ten years later. 149 women were evaluated by a psychiatrist 3 months postpartum and the children of 89% of these women were examined at eleven years of age. The study found out that the children of mothers with postpartum depression have significantly lower IQ scores and special educational needs, especially in mathematical reasoning. Also the study noticed that boys were more profoundly affected than girls (19).

During infancy the mother's ability to perceive the child's signals is reduced, just as the eye contact, mother smiling and interactivity is reduced. During Kindergarten age, the mothers tend to believe their children to be especially challenging, verbal communication is reduced and positive reinforcement is low (10).

As they grow older such children tend to have lower peer social competence, behavioural problems and lower school adjustment (6,16). They also tend to be drawn into their parents' problems and parentification may occur (10).

In general, mentally ill parents may have difficulty finding the right path of parenting and are often inconsistent in their rules and parenting style (1). Older children then often want to help and support their mentally ill parents (20), even though they may not understand why the parent has changed and feel afraid and guilty. They try to help but at the same time feel helpless, embarrassed and sad (3,8).

The everyday life is disturbed in families with mental illnesses. The parent may not be able to fulfil his or her duties, resulting in a loss of structure. But due to fear of stigmatisation and

bullying the children feel like they cannot talk to anyone outside the family about the illness and try to conceal their problems (8,20).

Concealing the problems and covering for their parents often includes taking over responsibilities in the household. Thereby, they may take responsibilities that exceed their emotional and cognitive maturity, as for example caring for younger siblings. This problematic progress is called parentification (2,7,8,21).

Another aspect is the family and social situation. Single parents are more likely to suffer from mental illnesses than married parents and children living with the ill parent in a single-parent household have a further increased risk for a negative outcome (22). Having a second parent who is mentally healthy and caring, has a buffering effect on the children and may decrease the risk of a negative outcome (23). A similar buffering effect can be achieved by social support from outside the family (24). Children of families prone to conflicts, like those with mentally ill parents (25), are however less included with their peers and often have fewer friends (26), aggravated by fear and burden of stigmatisation (8,27). Many adults who grew up as children of mentally ill parents describe negative emotions dominating their childhood such as feelings of “shame, depressed mood, fear of conflicts, feelings of abandonment, loneliness, insecurity, insufficiency, fear, deceit, lack of confidence, anger and envy of friends who had their parents at home. The grown-up children also reported difficulty in appreciating things that would ordinarily have made them happy, and feeling that things had lost their importance. Other symptoms described were stomach pain and difficulty concentrating” (28).

The lack of information about their parents’ diseases left them feeling unprepared. Some carry the mistrust, fear, guilt and other negative emotions they experienced as children into adulthood (17,29).

Apart from the mental health, the physical health is at risk in children of mentally ill parents as well. Children of mentally ill parents suffer from more injuries during their childhood and especially during their first year of life compared to other children of the same age. A Swedish study (30) published in 2020, analysed the risk of injury of 1 542 000 children born in 1996-2011 with a mother or father suffering from non-affective psychosis, affective psychosis, alcohol or drug misuse, mood disorders, anxiety and stress related disorders, eating disorders or personality disorders and compared the results to children of mentally healthy parents. The risk of injuries was categorized as transport injuries, falls, burns, drowning, suffocation, poisoning or violence at ages 0 to 17. The Swedish study found “Adjusted rate ratios at age 0-1 ranged from 1.28 (1.24 to 1.32) for fall injuries to 3.54 (2.28 to 5.48) for violence related

injuries. Common and serious maternal and paternal mental illness was associated with increased risk of injuries in children, and estimates were slightly higher for common mental disorders” (30). According to the Swedish study violence related injuries result from fights and physical, sexual and psychological abuse (30).

INTERVENTIONS AND PREVENTION

To reduce the children’s risk of suffering from mental illness themselves or suffering from consequences of their parents’ illness, interventions and preventions are necessary. Interventions can be directed at the family as a whole or solely on the child or children.

The goal of interventions is to reduce negative outcomes and psychosocial symptoms (31). Interventions can encourage the children to talk about their parent’s disease and their personal experiences and problems, the family and social situation and also encourage and remind them to be child-like and be with their peers (20). Interventions can have a preventive or therapeutic purpose, depending on the individual’s situation and needs. Preventive measures can be further subdivided into primary, secondary and tertiary (8). Primary prevention is the decrease of causes and triggers, resulting in a decreased risk of developing mental health issues. Secondary prevention is in cases where no disease symptoms are recorded yet but early signs are noted and the progression to a mental illness needs to be prevented. Tertiary prevention is the inhibition or slowing down of progression of a manifested disorder (8).

One intervention approach is directly and individually targeting the children to promote resilience and coping. Resilience is the mental capability of resistance and recovery from negative influences and experiences (1,3). It is not a learned trait and a person’s resilience can vary depending on the person’s situation and age. Some factors strengthening a person’s resilience are characteristics like being even-tempered, independent, confident and having good self-esteem, problem-solving skills, communication skills, good school performance, to believe in oneself and belief in self-efficacy, to have social skills and strategy and planning competence. Children with high resilience have `thick skin`, are not however invincible (1).

Coping on the other hand are cognitive and behavioural strategies and efforts to manage difficult situations (32). Children have coping mechanisms that help them deal with their mentally ill parents and the burden of it. These coping mechanisms can be divided into voluntary and involuntary. Voluntary coping focuses on firstly, primary control strategies to either change the stress-factor or the person’s response abilities, like problem solving or emotional regulation. Furthermore, secondary control is the acceptance and restructuring as adaptation and finally, avoidance where the goal is to change the focus away from the stressor.

Involuntary coping includes firstly involuntary emotional response as well as involuntary behavioural response to the stress-factor like impulse reactions. Secondly, involuntary disengagement like emotional numbing or unintentional avoidance of the stressor. Coping mechanisms that are dealing with the stressor rather than avoiding it are resulting in better adjustment and better outcome (33).

Many intervention techniques focus on enhancing coping mechanisms of the children and therefore improving their ability to deal with the situation and their ill parent.

One important intervention technique to enhance coping is communication. Often children are not well informed about their parent's disease, the reasons for that may for instance be shame, guilt, fear or lack of awareness of its importance (34). The children notice that something is wrong or has changed but they do not understand what exactly and more importantly why. This is true for all ages but the older the child, the more distinct is their perception of this. Therefore, age adapted information sharing about the parent's disease can reduce fear, shame and helplessness of the children and also, enable the development of a trustful parent-child relationship (8,20). When children understand their parents mental illness better, "they are less likely to blame themselves for the parental symptoms"(35). Hence, communication between the children and their parents but also with their parents' physicians is helpful, especially when the parent is hospitalized.

In a Canadian study 22 English speaking children of parents receiving treatment for depression, bipolar disorder or schizophrenia were interviewed about their experiences and knowledge of their parents' diseases. The study found that the children had limited knowledge and had not had an explanation of what was happening. They "had difficulty understanding hospitalization for a mental illness. Consequently, hospitalization was associated with physical illness and unwarranted fears that their parent was dying. This caused undue hardship for children" (34). According to them, communication is important to enhance understanding and prevent misunderstandings, as younger children were afraid of their parent dying whereas older children were more afraid of becoming mentally ill themselves (34).

In another Swedish study, grown-up children of mentally ill parents were interviewed about their experience with psychiatric services. The study found that the "children wished for more contact with the professionals at the psychiatric clinic, more information and more explanations concerning their parent's illness. They had wanted professional support for themselves and called for more initiative on the part of psychiatric services both during the hospitalization and afterwards" (28).

A Finnish study evaluated the Family Talk and Let's Talk About Children intervention techniques in 109 families (31). Family Talk is a family-based intervention strategy developed in the United States in the 1980's and is a "manualised, 7-session, strengths-based, psycho-educational, whole-family approach" focusing on communication within the family, understanding of the mental illness in question and improving the familial relationships. Furthermore, it is focusing on the children's resilience and coping mechanisms. Family Talk also encourages acceptance of social support (31,36,37).

In the United States the Family Talk intervention has been compared to a lecture intervention for parents and at the follow up 4-5 years later, the Family Talk intervention group has shown to be more successful measured by relatively better familial communication and children's understanding of the diseases. Both interventions have resulted in improvement in family functioning (38).

In the Finnish study, the Family Talk interventions "begins with two parent sessions covering personal and family history and psychoeducation about depression and resilience. An individual session with each child follows. [...] In the planning session, parents discuss with the clinician how to respond to children's questions, how to talk about depression with all family members present and how best to deal with possible family problems. In the family session the parents put mental illness into words for their children and answer children's questions with the clinician's help. Finally, the intervention is reviewed and plans for the future discussed in the follow-up session with parents"(31).

In the Let's Talk About Children intervention the discussion takes place with the patient and possibly his or her life partner. During the session, the child's situation and health is discussed and information on how the parent can support their child or children is provided. All parents, of both groups, received a guidebook as additional information source. Due to the high risk these children are exposed to, the Finnish researchers decided a no-intervention control group to be unethical. The Finnish study found that both forms of family-based interventions successfully improved the children's behaviour and negative emotions. In both groups the children's anxiety and hyperactivity rates decreased significantly. The family-based intervention can therefore be discussions with the whole family, or separate discussion with parents and children. "Even just a brief discussion with parents coupled with a guidebook to support parenting is associated with parental reports on favourable changes in children's well-being" (31).

Family can improve a child's resilience by providing security, a positive upbringing climate, good parent relationship as guidance and role model for the children, constructiveness,

flexibility and connectivity (1). Unfortunately, the parent's illness can sometimes complicate the family-based interventions, as "depression itself might contribute to lack of energy and motivation to participate" (31). An improvement in the parent's condition on the other hand has a direct, positive impact on the children health. Parental well-being must therefore be encouraged and attained (39).

Good family atmosphere and relationships are always essential but social support from outside the family can be an additional source for comfort and strength. Social and emotional support from society in general but also from friends and peers are essential for mental well-being. Positive experiences can be gained from school or leisure-time groups from sports or church for example (1).

Another intervention and support technique is the socioeconomic approach. Poor economic status is also an additional risk factor for mental illnesses like depression and an additional burden for the family (39), that can be charged by interventions and support organizations.

The effectiveness of interventions has been analysed in a study of thirteen trials including 1490 children. The results show that interventions significantly reduce the development of a mental illness in children of a mentally ill parents. The interventions used in the study included cognitive, behavioural, or psychoeducational techniques (40).

Support programs for children effectively increase the children's resilience and improve the outcome but still, it remains problematic to recruit children of mentally ill parents. Recruitment barriers are of multiple origins. Major problems are stigmatisation, limited knowledge and communication about the parents' disease, limited time and logistics (35). Parents with mental illnesses commonly feel guilty and have low self-esteem about their parenting, which hinders them to admit that they need help (17). Another problem is the recruitment strategy. In 2016 a study was performed to analyse the recruitment routes. Therefore, an international group of health and human service professionals with experience in recruiting children of mentally ill parents to join programs was formed. The participants were from Europe, northern America and Australia. According to the study the main recruitment routes are through school, the parents' mental health services and children and adolescent mental health institutions. Often recruitment is most effective when either the professional directly approaches the family, or through flyers and posters. The minority of patients was recruited through the internet. Diverse strategies are the most successful, meaning a

combination of personal recruitment by a trusted professional plus additional and repeatedly receiving flyers for further information and reminders of their importance (35).

To improve the recruitment success its problems need to be addressed. Stigmatisation is one of the main factors of avoiding help-seeking (35,41). Higher familiarity with mental illnesses results in less stigmatisation and a more positive attitude towards help-seeking (41,42). Furthermore, to overcome the logistic issues by providing a transport for example also increases participation in intervention programs (35). Some countries therefore suggest including help for parents with mental illness and their children into general polyclinics (43).

Another factor hindering good and timely interventions is the lack of collaboration between the different sectors involved in mental illnesses and child support, like adult psychiatry, child and adolescent psychiatry, pediatrics, gynaecology, social services and schools (44). Improved cooperation would result in better knowledge of the families in need (35). One example of cooperation possibilities are postpartum depressions, which up to 15% of mothers and 7% of fathers suffer from. A screening at pediatric primary care is suggested to identify these cases and offer prompt treatment to avoid a negative impact on the child (45,46).

The lack of consistency of programs, sometimes due to financial difficulties, is also believed to be a problem due to its lack of regularity and routine integration into services. Program perseverance helps health and human services to include it into their regular offer (35,43).

Additionally, a problem of voluntary prevention programs in Germany is that they are more commonly used by families with a lower risk and less often by families who would have a greater benefit from joining. Parents who are seeking help for their children are already aware of the situation and the dangers and risks it includes for their children. These children have considerate parents and therefore are most likely suffering less than children of parents unaware or ignorant to their children's needs (47).

GERMAN INTERVENTION SYSTEM

In Germany the intervention system for parents with mental illness and children of mentally ill parents is not regulated by the government, nor is it standardized nationwide .

Several separate organisations and professionals provide support either locally or across the country. Due to the federalist structure in Germany, a nationwide organisation must pass through administration of national, federal, and municipal levels. All levels must cooperate to provide broad spectrum help including the health and social sector (47).

Due to this lack of unity, many programs exist and some of those will be introduced and discussed below.

One program currently active in Germany is “Frühe Hilfen” (48–50) directly translated meaning “early help” and is an early childhood intervention program. It is a nationwide institution with a variety of support offers and information for families. Their target groups are families from pregnancy up to when the child is 3 years of age. The institution is not part of but aided by the federal ministry of families, seniors, women and children. As it is known that the first years of life have immense impact on development and mental health of children, this organisation tries to ensure a safe and healthy start of life. Their goal is to avoid negative impact on the children during their first years of life and avoid long-term consequences of parental mental illness during pregnancy and infancy. To achieve this they supply much parenting information on their website concerning for example why babies cry or why not to shake the baby, as well as digital leaflets with most important facts to know about every age group from birth to 3 years. They also provide a broad spectrum of local support. Trained midwives are offering to come to the families homes during pregnancy and throughout the first year of life to support the parents and teach correct handling of the baby. Frühe Hilfen also offers to find family godparents, who are volunteer workers providing support in everyday life or accompany the parents to appointments, like the regular check-ups at the paediatrician. Frühe Hilfen information centres are located in several cities across Germany and provide information about pregnancy, parenting, mental health and additional support possibilities. Parent-kid meetings and gatherings are opportunities for parents to meet each other and share experiences and provide social inclusion. Another local support offer is the so-called cry-walk-in-clinic, which are walk-in clinics designed to provide quick relief to exhausted and desperate parents of crying children, as they are at risk of mishandling their children out of desperation. Frühe Hilfen attempts to recruit patients through an interdisciplinary approach. Due to the early help approach the goal is for gynecologists and pediatricians to recognize and recruit families at risk. The cooperation with psychiatric institutions is however not sufficient and families with severe psychiatric disorders are not adequately supported by this program alone (48–50).

Another nationwide program is “CHIMPs” (8,51,52). CHIMPs is trying to establish a family-based intervention system with at least one local facility in every German state. Currently a total of 21 centres spread over 13 of the 16 states are participating in the CHIMPS-NET initiative. The aim of the intervention program is to improve mental health and life quality, intergenerational perspective sharing of the illness and its consequences, communication,

improved family relationships, overcoming of social isolation and improved social support as well as promoting acceptance of help. (51)

Generally the CHIMPS initiative laid out for children from 3 years until early adulthood and is not specific for the parents' mental illness but combined for different psychiatric disorders. It started as a preventive measure but has been expanded to include therapeutic measures and early signs recognition measures as well. The focus of CHIMPS counselling lies firstly on the management and coping strategies of the mental illness and secondly of quality of relationships in the family and with people outside the family. Therefore, meetings are held with the parents, the child and the whole family. Around 8 intervention sessions, including additional five to six diagnostic interviews for the child, are performed in approximately one year. Parent-meetings are, if possible, with both the mentally ill and healthy parent. The goal of these meetings is for the therapist to get an understanding of the mental illness in question and the severity of the illness, the family strategies of dealing with it and the family relationships, the couple dynamics and relationship and the parent-child relationship. Another important part is the developmental anamnesis of the child. Finally, the parents' hopes and goals for the interventions are discussed. The child-meetings are for each child individually and preferably without the parents. Children do not have the loyalty issue when talking to the professional alone and it is easier for most of them to talk freely and honestly. The goal is to discuss the child's subjective difficulties and problems with the family situation. Often a first diagnostic assessment is already possible too. The child counselling depends very much on the age of the child. Younger children do not express their feelings with words as much as older children do. Therefore, different games and activities like drawing or roleplay are used to communicate with the younger children and to understand their issues and perspective of the situation. In older children the dialogue becomes more important and especially from about 16 years of age, to treat them like grownups rather than children. The aim of these meetings is to discuss the parents' illness, the family situation and relationships and themselves, their strengths, resources and coping mechanisms, but also their problems and their dreams and hopes. The family-counselling is the main intervention method in CHIMPS. The perspectives of each family member and the insights of each individual meeting are brought together in the family sessions. According to the family's wishes and needs different aspects can be focused on and be discussed with professional supervision, including points of contention or current arguments. One important part is also the discussion of the mental illness itself and the causes and consequences with all family members because very often families do not talk about it much at home and in this setting for example misconceptions about guilt can be addressed and removed (8,52).

The current CHIMPS-NET scientific study divides their support into three levels. Firstly, a short preventive measure for healthy children and their families (CHIMPS-P) conducted by social workers. Secondly, for children with threshold range psychiatric and behavioural disturbances a mixture of preventive measure and therapy is offered for the child and his or her family (CHIMPS-MFT). Children who are already symptomatic will together with their families be invited to join family-oriented therapy conducted by a psychotherapist (CHIMPS-T). For children with logistic difficulties to join the program, a remote therapy option is available (i-CHIMPS). Recruitment for the study is achieved via interdisciplinary advertisement including adult psychiatric institutions. It is recommended by professionals and leaflets are available for the patients to take (51).

To increase their recruitment spectrum, representatives of the program advertise it at different, related institutions, like psychiatric hospitals or social services.

A third nationwide initiative is “Netz und Boden” (53–57) founded by Katja Beeck. As its name suggests the goal of this initiative is to catch children of mentally ill parents and put them back on their feet. Currently they have several local offices in all federal states in Germany. The initiative is aiming to improve nationwide support by offering seminars to other institutions or individuals about the risk these children are exposed to. They offer education through seminars, meetings or leaflets, about parents with mental illnesses and how the children can be helped best. Their education does not only focus on the children’s help, although that is a major part, but it also includes education about psychiatric disorders in general, different diseases and their characteristics. “Netz und Boden” further shares experiences from grown-up children of mentally ill parents and how they describe their childhood and the situation of having a parent with a mental illness. The organisation is also promoting books and statements of German celebrities’ discussion of this subject. Their target groups are not only families with mental illnesses but also their friends and social surroundings as well as institutions like kindergartens, schools, social services, hospitals, psychiatric hospitals and family courts. With increased awareness, recognition improves and possibilities for helping increase, and at the same time stigmatisation decreases (53–57).

The “Bundesarbeitsgemeinschaft Kinder psychisch erkrankter Eltern“ (58) is a federal working group founded in 2006. It aims to educate and publicise the problem of children of mentally ill parents and to increase awareness of their struggles and risks. The goal is further to encourage cooperation and development throughout the country. Therefore, the federal working group cooperates with individual, local initiatives or institutions across the country, connects them

and promotes communication. The institutions or working groups included can either aim to improve development of support for the parents with mental illness, their children or social support network. They can also aid the cooperation between existing programs and initiatives. Or lastly, the federal working group aids scientific studies and publications (58).

Additional to the nationwide programs, local initiatives like “YourCoach” and “AURYN” exist. “YourCoach” (59) is a local initiative in Marburg, Hessen. This program is for children and young adults between 12 and 24 years of age. The aim is to strengthen, support and encourage children of parents with mental illnesses to achieve their own life goals and to cope with the burden of their parents’ disease and the family situation. In this program every participant meets with a coach to discuss what goals the participant has, what role in the family he or she plays at home, how the situation can be improved and how to allow oneself room for dreams and development. Also, sharing information about the parents’ mental illness and its consequences is part of the program. The program recruits adolescents and young adults by leaflets and online advertisement. Interested persons can then contact the organisation and make an appointment to discuss the participation possibilities. At YourCoach the meetings are conducted by physicians and psychologists of the local hospital (59).

AURYN-groups (60) in Wiesloch offer group sessions for children of mentally ill parents. Children between 6 and 18 are invited to meet once per week for two hours in small groups of four to six children of a similar age. During twelve group sessions the aim is the encouragement to talk about their emotional perception of the situation and to create a safe environment to do so. Included are age adapted information sharing and education about mental illnesses and the origin of their parents’ behaviours. Other goals are relief of guilt feeling and parentification, as well as support for recreational activities. Also, participants are encouraged to establish self-confidence and independence and to promote their talents. Basically, the three main focuses are the illness, personal identity and social competence. The meetings are conducted by educational or therapeutical professionals.

AURYN additionally offers family-based meetings including the parents in the progress, helping them understand their child’s situation and improving communication in the family. It aims to relieve parents of feeling guilty as well as the children. The project provides help in establishing transparency and a trustful environment.

Even though AURYN is a preventive measure, children often show noticeable abnormal behaviour. Many children profit from being in a group with other children who are experiencing similar things at home.

The name “AURYN” is nowadays used by several initiatives, all of which are focused on the support of children of mentally ill parents but some vary in their offers and include more creative strategies as well (8,60).

Many of those organisations and project are financed by donations and participation is free for children and parents of affected families. Organization of funding of these programs is difficult not only in Germany but also in other countries, as for example Lithuania (43). For children who are symptomatic and in need of more individual help the German healthcare system provides inpatient and outpatient treatment in Children-and-adolescent-Psychiatry or outpatient therapies at registered psychotherapy offices.

To get an inside point of view of the system and how it is perceived by a professional working in this field, an interview with a German psychotherapist, called J (61), near Frankfurt am Main was specially conducted in preparation of this Thesis.

J worked at an initiative focused on children of mentally ill parents in Frankfurt am Main for five years and is now having his own registered psychotherapy office, therefore he can elucidate the situation from a professional’s perspective.

The organisation J worked for was paid by a mission of foundation, which is a common financial possibility for organisations that are not covered by government or sickness funds. They did not provide only traditional psychotherapy but a combination of it together with other methods, like including the parents and social surroundings more, providing home visits and social networking. Thereby this project tried to fill the gap of registered health care providers, as they often do not have the possibilities or budget to provide additional support. Thanks to the foundation, they were not reliant on reimbursement from sickness funds and therefore did not need to establish a specific diagnosis for the child but were able to help in the ways they saw fit, including preventive measures for children without any symptoms or signs of mental illness. The majority of children were however already suffering from psychiatric disorders or showing problematic traits. According to the interviewed psychotherapist, children without symptoms do not usually seek help or preventive measures, he believes that perhaps they have no need for it because the communication or social support is good enough to protect them.

To reach the children who need help and support, the project cooperated with psychiatric hospitals in Frankfurt and employees visited the hospitals regularly, to introduce their program to the patients and to advertise children help. By going to the hospitals and introducing oneself and the program, the hurdle of having to contact a stranger was lowered. This method is now commonly used by many of these initiatives due to its great success of reaching the families in

need of help. However, with this method children are only contacted through their parents' and this often brings difficulties because of the parents' feeling of guilt and failure and their fear to lose custody, especially in single parent households. Sadly, this is very relevant since, most typically, J recalls treating families with a single parent, mostly the mother, and one or more children (61).

Another method to reach children of mentally ill parents the initiative used was through social workers and the youth welfare office. Unfortunately, J says, it is very dependent on the specific social worker and whether they notice the need and recommend the available programs. Pamphlets are widely available at these offices, too. Connections to the public health department and local education authorities and schools, especially schools for children with special needs are also valuable. Rarely, parents research for these programs on the internet themselves. The interviewed professional assumes that families who are that aware of the problem and pro-active to support their children, usually do not have the biggest need for it. The support they want is help in telling their children about their mental illness, when and how to inform them. Age adjusted communication is an important factor of this. Nowadays, even some children's books discuss and explain mental illnesses.

To ease the particular problem of shame and guilt, some programs like "Auryn" do not mention mental illness in their title and therefore ease the hurdle of contacting them, J says (61).

The work of the initiative the interviewed worked for, included private sessions, family therapy, preventive measures, group therapy and basically whatever they saw fit.

In his registered psychotherapy office, J is still working with a lot of children of mentally ill parents but children who are symptomatic themselves already and have an established diagnosis. Therefore, he now provides traditional psychotherapy and gets paid from health insurances not foundations.

In Germany the healthcare system allows adolescents to get up to 180 hours of psychotherapy sessions. This may result in about 5 years of therapy and usually with the same therapist, if the relationship is good. This is only for sessions with a registered psychotherapist however and does not apply for these initiatives mentioned earlier, because it requires a diagnosis and does not include preventive but therapeutic measures. For children younger than 14 years of age, parents' permission is required in Germany.

Group sessions J says are generally good but also difficult with children and adolescents, because of the different ages and needs. In his office J offers single and family sessions depending on how he evaluates the situation and benefits of either method. Depending on the age, for adolescents for instance he sees greater benefits in talking to them alone, whereas for

younger children talking together or even mainly with the parents might be more beneficial, since change and improvement in parents' behaviour has major effect on the children's health as well (61).

During his years of working experience, J noticed that children who are looking after their mentally ill parent are commonly very mature for their age and often do not experience childhood and puberty like their peers. They are feeling responsible for the parent and family and often guilty when focusing on their own life. The parents' diagnosis and the severity of the disease also makes a difference according to him. From his experience, children of schizophrenic or bipolar mothers were having more conspicuous traits than children of depressive mothers.

In the project in Frankfurt as well as in his office, J does not usually attend siblings, since he and his colleagues believe it to be best to have one family member for therapy per therapist. This improves confidentiality because the child does not need to worry about what the siblings are saying about them and also it does not lead to conflict of the therapist by getting information from multiple sources. The child in question should never have the feeling of doubt, fear or second-rateness. In some situations, it might however be of benefit to have joined meetings with all children together, he says (61).

The main focus of the sessions is firstly the understanding of the parent's disease but according to J this is relatively quickly done. More difficult are issues like parentification, feeling of responsibility and guilt. Especially, since in most families these problems have evolved over a long period of time already and are therefore difficult to resolve. To explain parentification J likes to use a painting by Rene Magritte called "Der Geist der Geometrie" (62). The painting shows the body of a mother holding an infant on her arm, but the heads are switched, just as the roles are switched in parentification. Magritte's mother was suffering from a psychiatric disorder and the artist produced several pieces reflecting his childhood experiences of growing up with a mentally ill parent (61).



[Figure 1: Rene Magritte, Der Geist der Geometrie (L'esprit de geometrie), 1936/37 (62)]

Other issues that are being discussed in psychotherapy session, but also in other settings, are stigmatisation and tabooing, as they are general problems in society. The psychotherapist interviewed, regularly visits a local secondary school to inform and discuss about mental disorders and particularly suicide with teenagers, trying to increase awareness for and understanding of psychiatric diseases. One goal is to correct the belief that psychiatric disorders are simply a weakness of character, and the person just needs to pull themselves together. J noticed a huge desire of the students to talk about it and share personal experiences or feelings. Many are grateful for the possibility to discuss these topics and to understand others and their own emotions better (61).

When being asked about the main issues in this specific department in healthcare, J states as problematic that the German healthcare system does not have an institutional, nationwide system for children of mentally ill parents' but only separate projects and initiatives. His hope for the future is increased preventive measures. Additionally, when he is visiting local schools, J receives very good feedback and gratitude and would therefore wish for a broader inclusion of psychiatric disorders into the educational system. Perhaps starting with age adjusted information giving at primary schools already, to sensitize children about emotions and mental health and to decrease stigmatisation early on. According to J, better and broader education should be the main goal for improvement in Germany. Thereby, automatically decreasing stigmatisation, fear and guilt (61).

DISCUSSION

The incidence of children having mentally ill parents is one quarter in western society (2,3). This number reveals the importance of this topic, as these children have a scientifically proven increased risk of developing a mental illness themselves (1,3). As stated, this is on the one hand due to a varying in importance but nevertheless existing genetic predisposition and on the other hand environmental factors these children are exposed to. Mental health is an example of nature vs nurture. Genetics cannot be changed, but the environmental factors can be targeted to successfully improve the children's health (1,8–10).

Apart from becoming mentally ill themselves, these children are exposed to other risks, too. Parentification for instance is a dangerous consequence of children living with a mentally ill parent. It is not healthy for a child to take on too much responsibility and to grow up too quickly (7,8,10,17).

Also, a lack of structure and consistency can have consequences beyond childhood (1). To be able to provide good care it is important to provide proper risk evaluation and individualized support. Some problems are prevalent in most affected families however and can therefore be targeted in general. Parents with mental illness, especially in single-parent households, show impaired parenting skills resulting in a reduced quality of care (16,17,22). Also, to improve the parent-child relationship and build trust is an important issue to be targeted. Parents may need teaching in eye contact and verbal and non-verbal communication, as well as positive reinforcement (17). Furthermore this provides consistency for their children and a daily routine for the entire family. As it is important to improve the parent's health to be able to achieve successful family therapy, the parent's treatment should be a primary goal, as well.

Stigmatisation and feeling of shame must be reduced as much as possible, in order to make help-seeking easier and therefore reducing negative consequences of living with a mentally ill parent (8,35,41,43).

After doing the research for this Thesis I believe that the key component of successful intervention is communication. Communication on several different levels and for different purposes. One type of communication is education of the patient and their family as done in many of the projects described above. Informing and educating the entire family about the disease and possible consequences, as well as providing ideas for improvement and healthcare. Communication within the family is shown to be a major factor improving outcome. Honest and open communication about the disease and about everyone's feelings is very important. As stated above, children of mentally ill parents have expressed the wish to be informed (28). This results in better understanding and therefore improves coping (34,35). Communication within the family and the treating physician are a major coping strategies. This type of communication might be most successful in a psychotherapy setting, in order to have a helpful and guided discussion. It is therefore one of the key components of most intervention projects, like Chimps or Aurn (51,60).

As well as communication with the affected family, education of society is essential. Lectures to educate employees of social institutes like kindergartens, schools, churches or social- and youth welfare offices, are important. I believe improved understanding of psychiatric disorders and the health risks for children are essential for improved help providence. As being informed opens the possibility to recognize people in need of help. Therefore, talks at these institutions should be performed regularly, as the psychotherapist interviewed and other projects, already do (58,61). Children and adolescents are craving for information, especially when their own

family is affected. But even if they are not personally affected, most adolescents have heard of mental illness on social media and receive plenty of information which may or may not be scientifically correct. As the German psychotherapist who has been interviewed for this Thesis has experienced many times, students are very interested and eager to learn about and to understand psychiatric disorders (61).

This shows that the information sharing process needs improvement, within the families and in society. Greater education on these levels could not only improve recruitment but also result in a major decrease in stigmatisation thanks to an informed society. With knowledge understanding grows and fear declines.

Another component that needs improvement in Germany, but which is also a worldwide problem is not only providing help but recruiting families to join the programs and to accept help. As mentioned, improved communication is one part of it. Another major aspect that is not fully exhausted yet, is the cooperation between different facilities starting with obstetricians, gynaecologists and midwives, because neglect may already begin during pregnancy and has a crucial impact on infants. Later paediatricians can provide information and support for the parents. As paediatricians only see the children regularly within the first year of life, other facilities become more important after that. Kindergarten staff and teachers can detect need of help if they are trained and know what to look for. Same goes for friends of the parents as well as the children's. A multidisciplinary approach and a location at a general outpatient clinic may help to improve recruitment and reduce isolation (43).

In Germany, many good systems exist and can be found online or through leaflets. They target different groups, depending on the children's age, the parent's diagnosis or the severity of the situation but the parent needs to become active themselves in order to receive support, which is resulting in a lot of cases slipping through. So far there is no successful system to actively catch families at risk of negative outcome. One possibility to improve that particular problem could be mandatory, standardized questionnaires that every psychiatric patient must fill out, checking for children, their age, the family's social situation and presence of support.

Another problem in the German recruitment strategy is the media used.

Leaflets at psychiatric hospitals or social offices do not reach a lot of people. Older children are spending a lot of time on social media, which should therefore be used more both for recruitment and education. In that way children are also not dependent on their parents to organize the help for them. And then when the children are part of an intervention program, their resilience can be strengthened and coping strategies taught.

One final, major problem I have spotted in the German system and as has been pointed out by the interviewed psychotherapist (61) is the lack of a nationwide concept which results in a lower chance of reaching families in need of help. Communication is one thing but knowing what or who to recommend is essential to be able to offer help. Many Projects like „Frühe Hilfen“, „Chimps“, „Netz und Boden“, the federal working group and „Auryn“ exist and they appear to be doing a really good job for their individual target groups, but the problem is the variety and therefore the lack of uniformity. In a nationwide intervention program, with subgroups to ensure more individualized care, this state-system could be advertised across the country and win public awareness. Also, social workers, physicians, teachers, etc. would know what to recommend instead of providing a bunch of leaflets, if any at all. Concluding this paragraph, I believe that if a nationwide system and cooperation of different facilities exists, organisation of help will be a lot easier and a lot more efficient.

CONCLUSIONS

In conclusion, parents with a mental illness and their children's health is a neglected field of medicine. Genetic and environmental factors are equally important for the health prognosis of these children. A mentally ill parent does not only need treatment for themselves but care and support for the entire family. Many good offers to support families and children with a mentally ill parent are currently existing in Germany and other countries. But at the same time children usually only start seeing a psychotherapist when they are already symptomatic. The prevention system has therefore failed these children and they must rely on therapeutic care to achieve the best possible outcome for their health. Increasing the preventive and supportive measures comes at a cost of resources, but if established successfully it will reduce the need for therapeutic care in the long run.

Parents with a mental illness and their children's health is a field of medicine that requires a lot of work and attention to achieve the necessary changes.

RECOMMENDATIONS

To achieve changes towards better preventive care I recommend perhaps a nationwide system with more efficient organisation and continuity but at least increased professional information sharing and education of institutions as well as society, combined with modernization of recruitment strategies.

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