UNIVERSITÄTSKLINIKUM HAMBURG-EPPENDORF

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Gesundheitsbezogene Lebensqualität von Familien mit einem psychisch erkrankten Elternteil

Dissertation

Zur Erlangung des akademischen Grades Dr. rer. biol. hum.

an der Medizinischen Fakultät der Universität Hamburg

Vorgelegt von

Alina Radicke

2021 in Hamburg

Datum der Annahme durch die Medizinische Fakultät der Universität Hamburg:	18.10.2021

Veröffentlicht mit der Genehmigung der
Medizinischen Fakultät der Universität Hamburg.

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B	Standardized coefficients
b	Unstandardized coefficients
BIC	Bayesian information criterion
BSI	Brief symptom inventory
CI	Confidence interval
EM	Expectation maximation
CBCL 4-18	Child behavior checklist 4-18
CHIMPS	Children of mentally ill parents (refers to the CHIMPS study)
COPMI	Children of parents with mental illness
FB-A	General family questionnaire
FQCI	Freiburg Questionnaire of Coping with Illness
HRQoL	Health-related quality of life
ICC	Intraclass-correlation coefficient
ICD-10	International Classification of Diseases - 10th revision
OSSS-3	Oslo social support scale
M	Mean
n	Sample size
r	Pearson’s correlation coefficient
SD	Standard deviation
t	*t*-value, test value for *t*-tests
WHO	World Health Organization
YSR	Youth Self Report
χ^2(df)	Chi-squared (degrees of freedom)

1. Introduction

This dissertation examines the health-related quality of life (HRQoL) of families affected by parental mental illness. HRQoL research is still limited, particularly regarding the HRQoL of family members of people with mental illness. To fill research gaps, this dissertation compares the HRQoL of affected families with data from the general population, investigates the influence of selected HRQoL determinants separately for each family member, examines the utility of two widely used HRQoL questionnaires in the mental health setting, and explores the link between family members' HRQoL. The structure of this dissertation is in accordance with the guidelines of the doctoral office which requires the following sections: introduction, methods, results, discussion, and conclusion. The introduction provides an overview of the epidemiology of families affected by parental mental illness, the impact of mental illness on family members' HRQoL, the concept of HRQoL and its relevance in the mental health setting. Research objectives are formulated based on the research gaps that were identified from previous research. The subsequent literature review first explores the multidimensionality and subjectivity of HRQoL, then critically reviews past research on risk and protective factors that determine the HRQoL of parents with mental illness, their children, and partners, and discusses past research on the link between family members' HRQoL. The subsequent sections describe the methods (study design, sample characteristics, measures, data analyses) and the results. The findings of this research and their implications are then discussed and summarized in the conclusion.

1.1. Health-Related Quality of Life of Families Affected by Parental Mental Illness

Approximately 15-23% of families across the world have or had been composed of at least one parent who is affected by mental illness (Leijdesdorff, van Doesum, Popma, Klaassen, & van Amelsvoort, 2017; Plass-Christl et al., 2017b; Stambaugh et al., 2017). Research has consistently reported lower HRQoL for parents with mental illness (Comer et al., 2010; Kang, Rhee, Kim, Lee, & Yun, 2020; Law et al., 2005) their children (Dittrich et. al., 2018; Goetz et al., 2017; Hagen, Hilsen, Kallander, & Ruud, 2019) and intimate partners (Hsiao, Lu, & Tsai, 2020; Krattenmacher et al., 2014; Vadher et al., 2020; Zauszniewski, Bekhet, & Suresky, 2009). Lower HRQoL of families affected by parental mental illness has been attributed to high physical, psychological, social, and financial burdens as well as inadequate assistance from mental health care professionals (Freed et al., 2015; Hsiao et al., 2020; Kaplan, Brusilovskiy, O'Shea, & Salzer, 2019; Plass-Christl et al., 2017a; Wiegand-Grefe, 2012; Wiegand-Grefe et al., 2021).

In recent decades, HRQoL has been increasingly considered as an outcome to determine the psychological burden of demanding family conditions like the presence of mental illness (Coker et al., 2011; Kang et al., 2020). Furthermore, the concept of HRQoL has been used to evaluate an individual’s current ability to manage activities of daily living as well as the effectiveness of therapeutic interventions (Wiegand-Grefe et al., 2021). Hence, it is crucial to include HRQoL as a standard assessment in clinical practice in order to develop and evaluate adequate interventions. Regarding the content of such clinical interventions, it is important to identify modifiable risk and protective factors of HRQoL that can be addressed during the sessions. Clinical interventions should not solely focus on the pure alleviation of mental health symptoms, but also improve the patients’ satisfaction with familial, social, and occupational components. This is important as the reduction of mental symptoms may not reduce difficulties with daily activities, financial strains, stigmatization or loneliness (Narvaez et. al., 2008). Despite sharing some common factors, the HRQoL determinants may differ for parents with mental disorders, their children and intimate partners. Thus, the individual periodization of HRQoL determinants should be kept in mind when developing interventions for mental health patients and their relatives. For this reason, the following literature review and the subsequent statistical analyses of the research objectives explore the HRQoL of each family member separately and considers multiple rating perspectives. This dissertation then provides a subordinate interpretation of the statistical results and their implications.

There are several research gaps that this dissertation aimed to overcome. Those gaps relate to HRQoL research involving parents with mental illness, their children and partners as well as to previous studies examining the association between family members’ quality of life. Several studies have investigated the HRQoL of adults with mental illness, but less is known about those who are also parents. In contrast to non-parents, parents with mental illness may not only have to deal with mental symptoms but also with their implications for their family. Parents with mental illness may experience additional stressors, but they also may possess protective resources that non-parents do not have such as a supporting family that motivates them to seek and adhere to treatment. To analyze HRQoL of parents with mental illness, research should investigate the utility of HRQoL instruments that are applicable to this patient group. A commonly used HRQoL instrument in clinical populations is the EQ-5D (Rabin et al., 2011). It is timesaving and can easily be integrated into clinical practice. However, the EQ-5D has primarily been tested in samples with physical disabilities. Its utility in populations with mental illness has been controversially discussed and inconsistent results have been reported (Brazier, 2010; Mulhern et al., 2014; Papaioannou, Brazier, & Parry, 2011; Sonntag et al., 2013). This dissertation aims to extend previous research not only by including family-related HRQoL determinants but also by enhancing knowledge on the utility of the EQ-5D in populations with mental illness (Rabin et al., 2011). The results can assist clinicians, policymakers, and economists to gain a better understanding of the patients’ well-being and to evaluate the clinical and cost effectiveness of treatments with appropriate HRQoL instruments.

Research on child HRQoL is generally limited, especially regarding children that are affected by parental mental illness (Hagen et al., 2019; Plass et al., 2016; Wallander & Koot, 2016). Studies that examined the HRQoL of children of parents with mental illness (COPMI) have mostly based their conclusion on bivariate correlational research that neglected the multidimensionality of HRQoL. The inclusion of multiple HRQoL determinants in regression analyses is still exceptional (Plass et al., 2016). Empirical research with multiple regression analyses is needed to raise the awareness for this young population at risk to suffer from low quality of life and mental health, and to help them with appropriate psychological interventions (Hagen et al., 2019). Moreover, the CHIMPS (children of parents with mental illness) project ‘Implementation and evaluation of a family-based intervention program for children and adolescents of parents with mental illness’ aimed at the early identification of COPMI with low quality of life and mental health, and to improve those outcomes by means of a family intervention (Wiegand-Grefe et al., 2021). The early identification and treatment of COPMI at risk is important to prevent an unfavorable psychological development and high financial costs related to the health care system (Kilian et al., 2017; Reedtz et. al., 2019; Waldmann et al., 2021; Wiegand-Grefe et al., 2021). Beyond that, this is the first study that has systematically investigated child-parent agreement regarding child HRQoL when parents were formally diagnosed with a mental illness. Past research has almost exclusively assessed the children’s quality of life with parent proxy-reports (Berman et. al., 2016; Cremeens, Eiser, Blades, 2006). Studies that have examined child-parent agreement regarding child HRQoL had several methodological limitations that have often prevented a conclusive causal inference. For example, they often had small sample sizes, explored agreement rarely in multivariate analyses and mainly used bivariate Pearson’s product-moment correlational research to analyze results (Berman et al., 2016; White-Koning et al., 2007). The latter has been criticized as it is only a measure of correlation and a nonideal measure of interrater reliability (Koo & Li, 2016). Koo and Li (2016) have proposed that the intraclass correlation coefficient (ICC) should be used instead because this index reflects both degree of correlation and agreement between assessments of the same construct. The investigation of the magnitude and direction of child-parent agreement as well as the identification of predictors of disagreement is relevant, especially when parents are asked to make health care decisions for their underaged children, and when the parental perspective on child HRQoL differs from the children’s point of view (Berman et. al., 2016; Upton, Lawford, & Eiser, 2008).

Other research gaps relate to the HRQoL of the partners of parents with mental illness. Although the perspective of the intimate partners and their quality of life have gained more attention in the past decades, systematic research that provide a valid assessment of quality of life of caregivers is still limited and has almost exclusively focused on family members of people with schizophrenia. The sample of this project covers various types of mental disorders and may provide a more general picture of themes that are central to the families’ quality of life. Research indicates that a person’s quality of life is influenced by the quality of life of close others (Bergelt, Koch, & Petersen, 2008; Caqueo-Urízar et al., 2017; Hjärthag, Helldin, & Norlander, 2008; Parabiaghi et al., 2007; Perlick et al., 2006; Rhee & Rosenheck, 2019; Sun et al., 2019). Thus, steps towards improving the partners’ quality of life may enhance their ability to provide good care for the mentally ill person and result in more favorable outcomes for the whole family (Caqueo-Urízar et al., 2017; Vasilopoulou & Nisbet, 2016).

Despite the call for more research on this topic, only a few studies could be identified that have explored the association between the quality of life of relatives and patients in families affected by mental (Caqueo-Urízar et al., 2017) or physical illness (Goldbeck & Melches, 2005). Only one of the mental illness studies has directly investigated quality of life in patients and family caregivers including intimate partners and children (Caqueo-Urízar et al., 2017). However, this study included only families of patients with schizophrenia, which limits the generalizability of the results to other mental diagnoses. Furthermore, the correlations between HRQoL reports were not separately analyzed for partners and child caregivers although they have very different relationships with the patient. Other related studies have examined the impact of the mentally ill patients' quality of life on family burden but not on the family members' quality of life (Hjärthag et al., 2008; Parabiaghi et al., 2007; Perlick et al., 2006; Rhee & Rosenheck, 2019). This dissertation extends previous research by analyzing the HRQoL correlations between patients with a broad range of mental disorders, their partners and children.

In summary, there are many families that are affected by parental mental illness (Leijdesdorff et al., 2017) and those families are at increased risk to experience lower HRQoL compared to the general population (Hagen et al., 2019; Kang et al., 2020; Vadher et al., 2020). This dissertation aims to overcome the presented research gaps by investigating the HRQoL of parents with mental illness, their children and intimate partners, and by examining the impact of modifiable risk and protective factors that are associated with HRQoL of family members. Moreover, this dissertation explores the utility of the generic HRQoL instrument EQ-5D in families affected by mental illness, and whether child self-reported HRQoL on the KIDSCREEN-27/10 deviates from the parents' proxy-reports. Lastly, this dissertation examines the link between the HRQoL of family members affected by parental mental illness and explores the magnitude and direction of those associations.

2. Literature Review

2.1. The Concept of HRQoL

HRQoL has increasingly been used as an outcome measure to determine the impact of mental illness on familial, social and occupational settings, and to measure an individual's current functioning and the effectiveness of clinical interventions (Coker et al., 2011; Kang et al., 2020; Wiegand-Grefe et al., 2021). HRQoL determinants include but are not limited to satisfaction with physical, psychological and social aspects (Ferrans et. al., 2005). The multidimensionality of HRQoL has been illustrated by the conceptual model of Ferrans et al. (2005) that is presented in *Figure 1*. The authors defined overall HRQoL as a construct that covers biological functioning, subjective symptoms (i.e., cognitive, emotional and physical), functional status (i.e., physical, psychological, social, and role functioning), general subjective health perceptions. Those five components are influenced by individual and environmental characteristics (Ferrans et al., 2005). The HRQoL model by Ferrans et al. (2005) has been recommended by researchers as it adds individual and environmental characteristics to the original Wilson and Clearly model in order to provide a more comprehensive understanding of HRQoL (Bakas et al., 2012). Although this model has primarily been used to evaluate HRQoL of patients with chronic diseases, it can also be applied to patients with mental illness and to the general population (Ferrans et al., 2005; Ojelabi, Graham, Haighton, & Ling, 2017).

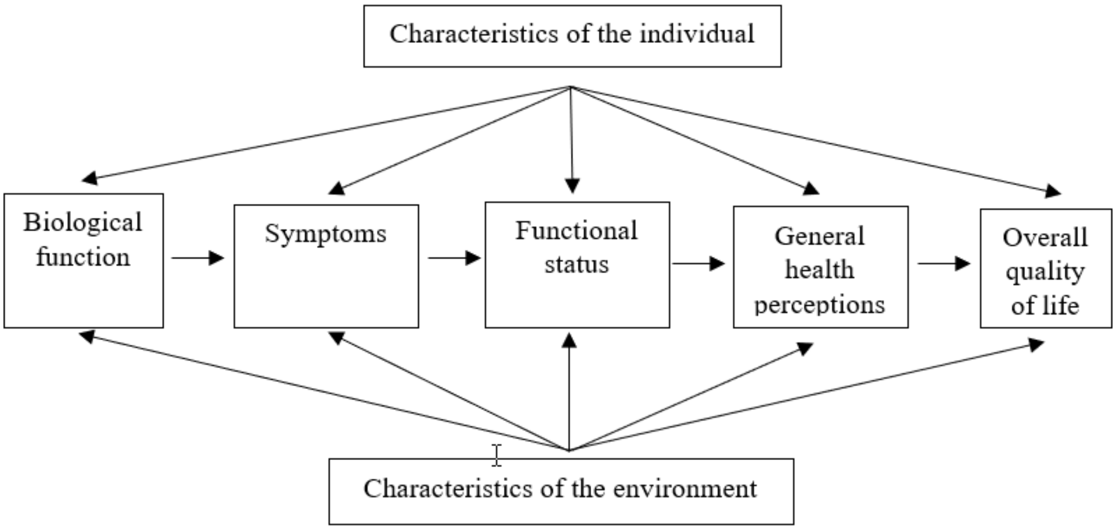

Figure 1: Health-related quality of life concept by Ferrans et al. (2005)

The multidimensionality of HRQoL allows domains with a positive impact on HRQoL to compensate for the negative influence of others. For example, even when children experience family dysfunction due to their parent's mental disorder, their HRQoL may not be considerably lower compared to peers due to a strong supportive social network. Generally, the priority of each HRQoL determinant depends on individual values, preferences and needs. Those can vary with the person's age, gender, culture or professional status as well as health characteristics and living circumstances (Bowling & Gabriel, 2004; Kivits, Erpelding, & Guillemin, 2013). For instance, while pediatric HRQoL research has especially emphasized family and peer relationships, autonomy and independence, young adults tend to prioritize work and social relationships, and elderly people tend to perceive health, social participation and independence in activities of daily living as central components of their HRQoL (Bowling & Gabriel, 2004; Ravens-Sieberer, 2006; Soósová, 2016).

Paradoxical reports of individuals who report relatively high quality of life despite serious disabling mental symptoms emphasize the dynamic nature of quality of life concepts and the importance of personal experience with disability in defining the self, the perception of the surrounding environment and social relationships (Albrecht & Devlieger, 1999). People may consciously or unconsciously accommodate to deteriorating circumstances, whether in relation to health, socioeconomic or other conditions (Bowling & Gabriel, 2004). Explanations for the so called 'disability paradox' include the reprioritization of HRQoL components, the redefinition of the concept of HRQoL as well as people's effort to achieve cognitive consistency (Blome & Augustin, 2015; Bowling & Gabriel, 2004). Attitudes towards quality of life can also be modified through coping, expectancy, optimism, self-control and self-concept (Allison, Locker, & Feine, 1997). Hence, it may be that families affected by parental mental illness adjust to illness-related challenges and are as satisfied as the general population with their HRQoL.

The following sections critically review past research on factors that are associated with HRQoL of parents with mental illness, their children and partners. The multidimensionality of HRQoL as well as individual differences between family members in terms of HRQoL determinants are thereby considered.

2.2. HRQoL of Parents with Mental Illness

Worldwide about 971 million people suffer from some kind of mental illness (James et al., 2018). The most common mental disorders in adulthood refer to two diagnostic categories: depressive disorders and anxiety disorders (World Health Organization, 2017). The World Health Organization (WHO) has estimated that 4.4% of the world's population suffer from depression, nearly the same number again is affected by anxiety disorders (World Health Organization, 2017). Numerous studies have consistently reported lower quality of life in adults with mental illness compared to the general population, including those who are also parents (Comer et al., 2010; Kang et al., 2020; Krattenmacher et al., 2014; Law et al., 2005). The parenting experience can affect the HRQoL of adults with mental illness both positively and negatively (Yu et al., 2019).

Starting with the positive aspects, a qualitative study by van der Ende et al. (2016) showed that children may enrich and structure the mental patients' lives and distract them from their symptoms. Many of those parents reported a heightened sense of responsibility and more social contacts through their children's friendships. In addition, they were more motivated and committed to psychotherapy (van der Ende et. al., 2016). The sample size of this qualitative study was rather small (*n* = 19), however, studies with larger sample sizes indicate similar effects. A longitudinal study from the United States analyzed a sample of 3142 participants who underwent substance abuse treatment. 32% of the mothers and 19% of the fathers in this sample reported that they were in treatment to regain custody of children. Thus maintaining or regaining child custody constitute an important motivation for parents to seek and adhere to clinical treatment (Marsh & Cao, 2005). Other researchers showed that parents with mental illness may experience personal growth through childrearing (Oyserman et. al., 2004) and benefit from their family's emotional and practical support (Helbig et. al., 2006).

On the negative site, family-related stress can diminish ones' HRQoL. All parents experience stress ranging from daily hassles to chronic stress at some time. It may result from children's characteristics (e.g., disobedient behavior, difficult temperament), the parents' own characteristics (e.g., mental health, maladaptive coping), their perception of parenting and (in)competence, as well as from contextual factors like poverty or limited assistance in childcare (Abidin, 1992; Belsky, 1984).

The experiences of parents with mental illness resemble those of healthy parents in many aspects. However, the presence of a mental disorder poses some additional challenges. Parents with mental illness have to deal not only with their disabling symptoms but also with their impact on family, social and occupational life. Mental illness can exacerbate parents' efforts to fulfill multiple role demands like being a good parent, partner and worker (Nicholson et. al., 2001). Parents with mental illness face a number of organizational challenges through their psychopathology that aggravate their efforts to coordinate family schedules. Mental symptoms and their treatment consume time and energy and can interfere with family appointments (Nicholson et. al., 2002). For example, parents with substance use disorder spend a lot of time getting, using, or recovering from the substance use (American Psychological Association, 2013). Their substance abuse can further cause non-adequate responding to the child's needs (Raitasalo & Holmila, 2017) ranging from struggles to organize the child's leisure activities to serious neglect. Furthermore, parents with mental illness frequently experience adverse psychosocial outcomes like severe financial strains and unemployment, and report poor physical and mental health, many stressful life events, and a high prevalence of custody loss (Kaplan et al., 2019; Luciano, Nicholson, & Meara, 2014; Nicholson et al., 2002). The family life and marriage may suffer under the adverse psychosocial circumstances, just as those of healthy parents. However, as opposed to healthy parents, parents with mental illness tend to judge themselves harshly against unrealistic standards and are prone to interpret daily stressors as illness-related personal deficits, thereby decreasing their mental health and quality of life (Nicholson et al., 2001). Parents' HRQoL may also be reduced when their children show signs of mental illness (Foldemo, Gullberg, Ek, & Bogren, 2005; Plass-Christl et al., 2017b; Vasilopoulou & Nisbet, 2016). Children's mental illness may be accompanied by additional stressful family situations, parents may have difficulties to manage the children's treatment appointments and medication regimes in addition to their own, and they may experience stigmatization and feelings of self-blame (Moses, 2010).

2.2.1 HRQoL Determinants of Parents with Mental Illness

2.2.1.1 Characteristics of Parental Psychopathology

The characteristics of psychopathology influence an individual's HRQoL. Most quality of life research in this area has focused on adults with schizophrenia, thus the generalizability to a broader group of patients with mental illness is limited. Nevertheless, there is agreement on some aspects of psychopathology that affect the patients' quality of life, such as illness duration, symptom severity, premorbid adjustment, and psychiatric comorbidities.

Results from an Australian health survey with a representative sample of almost 9000 respondents indicate that a longer duration of mental illness is associated with worse HRQoL outcomes across various mental disorders, even after health perceptions, functioning, and comorbidities were taken into account (Busija, Tan, & Sanders, 2017). Findings of a recent meta-analysis indicate that adults with psychotic disorders report lower quality of life when they experience a longer duration of untreated psychosis and more severe symptoms (Watson et al., 2018). A higher symptom severity resulted likewise in dissatisfaction with quality of life, daily activities, role functioning and social relationships among patients suffering from severe depressive symptoms (Ay-Woan, Tsyr-Jang, & Ping-Chuan, 2006; Kuehner, 2002). Some symptoms appear to be more predictive of quality of life than others. For example, the quality of life of approximately 90 outpatients with schizophrenia or schizoaffective disorders was worse when patients had more severe depressive and negative symptoms, but subjective life satisfaction was not predicted by positive symptom severity (Narvaez et al., 2008).

Besides symptom severity and illness duration, premorbid adjustment appears to be predictive of quality of life. Premorbid adjustment has been defined as a person's capacity to make social and intimate relationships as well as academic achievements before the onset of psychosis (Torgalsbøen, 1999). A study involving almost 50 Iranian patients with first psychotic episodes validated previous research (MacBeth & Gumley, 2008; Melle, Friis, et al., 2005) by showing that poor premorbid psychological adjustment was associated with poor quality of life and more severe negative symptoms (Mahmoodi-Gharaei et al., 2010). A systematic review concluded that the effect of premorbid adjustment upon quality of life increases over follow-up periods of up to 8 years and appears to be even more important than the duration of untreated psychosis (MacBeth & Gumley, 2008).

Another aspect related to HRQoL of patients with mental illness appears to be the presence of comorbid psychiatric diagnoses. Patients with psychiatric comorbidity view their HRQoL more negatively than patients without psychiatric comorbidity (Lozano et. al., 2017; Melle, Haahr, et al., 2005; Narvaez et al., 2008). It has been suggested that treating only a part of the problem, namely only one mental disorder, is insufficient for improving the patient's quality of life (Lozano et al., 2017). difficulties Patients with multiple psychiatric diagnoses show more social, interpersonal and legal problems, employment issues, make more use of emergency services (Curran et al., 2008; Martín-Santos et al., 2006), have a higher risk of relapse after treatment and drop out of treatment earlier (Compton et. al., 2003; González-Saiz et. al., 2014; Lozano et al., 2017). Consequently, there has been a call for integrated treatments to treat psychiatric comorbidity along with the primary diagnosis to improve patients' quality of life (Lozano et al., 2017).

2.2.1.2. Parental Coping Behavior

Parents have an individual understanding of their own mental illness and the distress associated with it. Their personal attitudes towards psychopathology and their coping behavior influence not only the course and outcomes of their mental illness (Heffer & Willoughby, 2017; Thompson, Fiorillo, Rothbaum, Ressler, & Michopoulos, 2018), but also their HRQoL (Vollrath, Alnæs, & Torgersen, 2003). Cognitive and behavioral coping efforts aim at the reduction and management of stressful situations that exceed one's resources (Van den Bos, 2007). The transactional theory of Lazarus and Folkman (see *Figure 2*) proposes that the intensity of a stress reaction is mediated by primary cognitive appraisal that determines whether the stressor poses a threat or challenge. Threatful situations activate the secondary appraisal, which involves the identification and evaluation of individual coping resources (e.g., self-efficacy, optimism), situational variables and coping styles (e.g., prior coping experiences) (Cooper & Quick, 2017; Folkman & Lazarus, 1984). Lazarus and Folkman's (1984) stress and coping theory suggests that coping strategies aim to either directly manage the stressor or regulate emotions. The outcome of the coping effort along with new information from the environment results in cognitive reappraisal that evaluates whether the coping strategy has successfully reduced or eliminated the stressor, or whether the coping strategy needs adaption (Folkman & Lazarus, 1984).

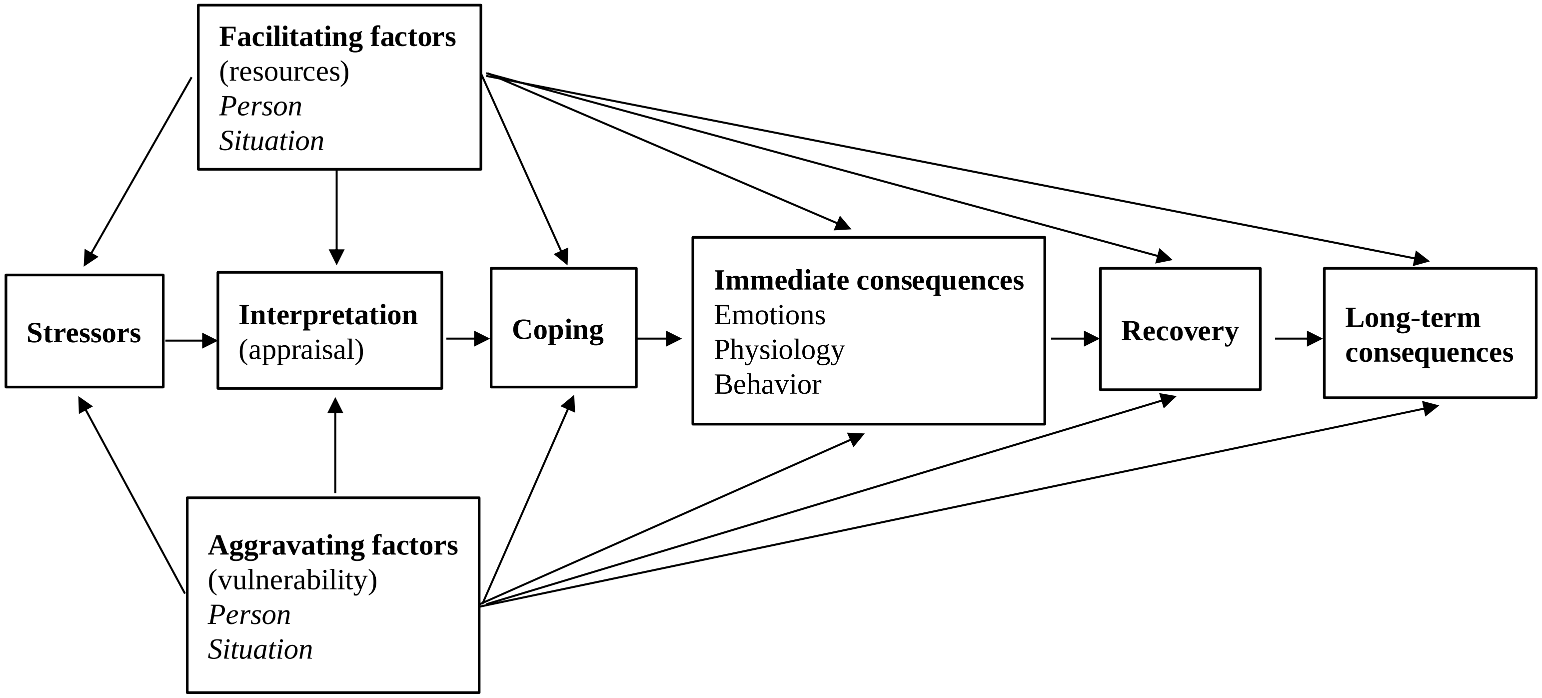

Figure 2. Stress management by Folkman & Lazarus (1984)

Parents can react to stress by applying a range of coping strategies, whereby some strategies appear to be more adaptive than others. Adaptive coping means that an individual is able to decrease the adverse effects of life stressor immediately and reduce the likelihood of its occurrence in the future. Adaptive coping operates as a protective factor for one's well-being and it promotes good mental health (Griva & Anagnostopoulos, 2010; Schwarzer & Schwarzer, 1996; Thorne, Andrews, & Nordstokke, 2013). Adaptive coping includes active problem-oriented strategies (e.g., making a plan of action to handle the mental illness and its impact on family, social and occupational life), the active emotional and behavioral social exchange, the emphasize on one's strengths and positive attributes, and the focus on factors that promote self-growth (Draine & Solomon, 1995). Other adaptive strategies are the use of instrumental support, positive reframing, acceptance and the use of humor (van der Sanden, Pryor, Stutterheim, Kok, Bos, et al., 2016). When parents with mental illness cope adaptively their symptom severity and illness duration decreases over time, they show less comorbid psychiatric symptoms and report less symptom burden than people who cope in maladaptive way (Meyer, 2001). Moreover, parents employing adaptive and pro-active coping show better adaptions to their mental health condition as demonstrated by a web-based correlational study with 266 adult parents with bipolar disorder. Active parental coping and dispositional optimism were positively associated with better adaptation to the mental disorder, whereas denial (maladaptive coping) impaired the adaptation (Peay, Rosenstein, & Biesecker, 2013). Better adaption may in turn improve the patients' quality of life in spite of mental restrictions through redefining life satisfaction and reprioritizing quality of life components (Ubel, Peeters, & Smith, 2010; Ubel & Smith, 2010). The adaptive coping of parents with mental illness has also positive effects on their families. It can reduce the family burden and stigmatization for their psychiatric condition (van der Sanden, Pryor, Stutterheim, Kok, & Bos, 2016), thereby improving the family members interpersonal relationships (Crowe & Lyness, 2014; Kreisman & Joy, 1974) and quality of life (Lefley, 1989; Rüsch, Corrigan, Powell, et al., 2009; van der Sanden, Pryor, Stutterheim, Kok, & Bos, 2016).

In contrast do adaptive coping, maladaptive coping strategies mitigate the negative impact of a stressor only temporally and can even reinforce distress (van der Sanden, Pryor, Stutterheim, Kok, & Bos, 2016). Maladaptive coping includes avoidance, denial, self-blame, substance use, self-distraction, behavioral disengagement and venting negative emotions (van der Sanden, Pryor, Stutterheim, Kok, & Bos, 2016). In the long term, those maladaptive coping strategies are ineffective in reducing both individual and family distress (Krägeloh, 2011; Moore, Biegel, & McMahon, 2011; van der Sanden, Pryor, Stutterheim, Kok, & Bos, 2016). Maladaptive coping strategies are associated with poor mental health outcomes (Draine & Solomon, 1995; Lee, Nezu, & Nezu, 2014; Mohr et al., 2014) and HRQoL (Vollrath et al., 2003).

Which coping strategy works best depends on situational demands. In general, individuals who are flexible in their coping efforts better adapt to stressful situations than people whose coping repertoire is more rigid (Fink, 2000).

Over the past 30 years, research has identified a number of factors that affect the stress appraisal and the subsequent selection of the coping strategy. While some factors are more general like personality, cognitive functioning, social environment, cultural and familial influences, age and gender, some factors directly relate to mental health symptoms (Meyer, 2001). Patients are more likely to use adaptive coping strategies (e.g., active problem-oriented) when they accept their illness and when they feel able to control a stressful situation (Lazarus & Folkman, 1984; Schüssler, 1992). In contrast, when patients perceive a stressor as unchangeable and uncontrollable, and when they do not accept their mental illness, coping strategies focusing on regulation emotions are more likely to be used (Lazarus & Folkman, 1984; Schüssler, 1992). Patients with mental illness often show cognitive biases that hinder their self-confidence and the acceptance of mental illness, thereby increasing the probability to use maladaptive coping strategies. Cognitive biases are defined as deviations in information acquisition, processing, and appraisal (Moritz et al., 2010). Research has found that people with anxiety disorders show cognitive biases in attention an interpretation of stimuli that further increase their psychiatric vulnerability. They tend to overestimate threats and favor the processing of emotionally negative information (Ouimet, Gawronski, & Dozois, 2009; Stapinski, Abbott, & Rapee, 2010), while underestimating their coping resources (Stapinski et al., 2010). Some studies have even found a selective memory retrieval in anxious people that favors negative information (Herrera, Montorio, Cabrera, & Botella, 2017). Cognitive biases play also an important role in the formation and maintenance of delusions, in particular persecutory ideation (Bell, Halligan, & Ellis, 2006; Freeman, 2007). People suffering from schizophrenia are more likely than healthy or psychiatric controls to jump to conclusions (Moritz & Woodward, 2005) and to neglect disconfirmatory evidence for decision making (Woodward, Buchy, Moritz, & Liotti, 2007). Across different psychiatric diagnoses, people with mental illness generally show an impaired ability to recognize a wider range of possible coping strategies and are they are more inclined to adapt maladaptive strategies due to a negative emotionality (Cohn, Fredrickson, Brown, Mikels, & Conway, 2009; Fredrickson, 2009; Gloria, Faulk, & Steinhardt, 2013; Gloria & Steinhardt, 2016).

Differences in diagnoses and symptomatology affect not only how people with mental illness appraise stressors, but also the way they cope with distress. To cope with auditory hallucinations, patients with psychosis tend to modulate social contacts, employ sensory stimulation, increase their physiological activity and use cognitive reframing (Knudson & Coyle, 1999; Meyer, 2001; Yagi, Kinoshita, & Kanba, 1991). It has been suggested that patients with schizophrenia prefer the enhancement of physical arousal to cope with psychotic symptoms over seeking social support because they have difficulties with interpersonal contacts (Meyer, 2001; Smith, Bellack, & Liberman, 1996). Compared to psychiatric controls they have difficulties to develop and maintain interpersonal relationship, to understand social contexts (Dodell-Feder, Tully, & Hooker, 2015), and to use assertive social behavior in response to negative affect (Smith et al., 1996). In contrast to patients with psychosis, people with depression usually feel a lack of energy and thus prefer coping by modifying thought contents (Meyer, 2001; Yagi et al., 1991). People suffering from anxiety disorders commonly use coping through escape-avoidance, self-blame and self-control (Panayiotou, Karekla, & Mete, 2014). Worrying is one form of cognitive avoidance frequently used by anxious people because it inhibits the experience of aversive images or arousal (Borkovec, Alcaine, & Behar, 2004; Panayiotou et al., 2014). Although coping strategies such as escape-avoidance may be effective in the short term by relieving distress, they contribute to the persistence of anxiety symptoms by preventing the exposure to the feared situation, hinder extinction and reduce self-efficacy beliefs (Mennin, McLaughlin, & Flanagan, 2009). Patients with substance use disorder are also more likely to use more maladaptive coping strategies than the general population (Marquez-Arrico, Benaiges, & Adan, 2015; Pence et al., 2008), which increase the severity of substance dependence (Hruska, Fallon, Spoonster, Sledjeski, & Delahanty, 2011). They generally tend to employ disengagement coping strategies (Adan, Antúnez, & Navarro, 2017) that significantly diminish their quality of life (Boelen & Prigerson, 2007; Latham & Prigerson, 2004; Masferrer, Garre-Olmo, & Caparrós, 2017). The maladaptive coping tendency of patients with substance dependence seem to be enhanced when patients had experiences of traumatic life events (Caparrós & Masferrer, 2021), and when they had an earlier age of substance use onset, probably because this subgroup has fewer interpersonal skills and thus a reduced access to a supportive social network (del Mar Capella & Adan, 2017).

In conclusion, parents affected by mental illness experience many stressful situations. Their stress appraisal and coping behavior affects their HRQoL (Vollrath et al., 2003) and mental health (Heffer & Willoughby, 2017; Thompson et al., 2018). Whereas adaptive coping promotes quality of life and mental health (Griva & Anagnostopoulos, 2010; Schwarzer & Schwarzer, 1996; Thorne et al., 2013), maladaptive coping is associated with opposing outcomes (Draine & Solomon, 1995; Lee et al., 2014; Mohr et al., 2014; Vollrath et al., 2003). Adults with mental illness are more likely than healthy controls to use maladaptive coping strategies due to cognitive biases that impede their self-confidence in stress management and coping resources (Ouimet et al., 2009; Stapinski et al., 2010).

2.2.1.3. Family Functioning

‘Family functioning refers to the social and structural properties of the global family environment. It includes interactions and relationships within the family, particularly levels of conflict and cohesion, adaptability, organization, and quality of communication’ (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010). It has been suggested that family support affects quality of life both directly and indirectly through parental stress levels (Zeng, Hu, Zhao, & Stone-MacDonald, 2020). On the one hand, family members can provide social support and positive experiences, but on the other hand family members can cause distress and diminish the parents’ HRQoL (Wang, Chen, Tan, & Zhao, 2016).

A person’s mental disorder can strain intimate partnerships. Parents with mental illness are more likely to be single, separated or divorced than their healthy peers and are more likely to provide single-care for their children (Mowbray et al., 2000; White et. al., 1995). The hazard of divorce is significantly higher when intimate partners are mentally distressed (Idstad et al., 2015). In general, separated and divorces people report significantly lower HRQoL than peers who are married or have de facto relationships (McCaffrey, Kaambwa, Currow, & Ratcliffe, 2016). Partnership seems especially important for parents with mental illness, probably because partners can assist in child-rearing, house chores, and provide emotional and practical support. A German health survey with over 2800 participants found that the absence of partnership was associated with increased rates of all common disorders in parents with mental illness, but not in non-parents with mental illness, suggesting that partnership appears to be particularly important for parents as it does not affect prevalence rates of mental disorders in non-parents (Helbig et al., 2006). However, the addition of a partner may not always improve parents with mental illness' quality of life as demonstrated in a study by Mowbray and colleagues, in which mothers described their children's fathers as one of the major day-to-day stressors in their lives (Mowbray et al., 2000).

Irrespective of the presence of an intimate partner, research has consistently demonstrated that people with mental disorders are more likely to live in dysfunctional families that are characterized by family discord, lower levels of expressiveness and affective involvement, and impaired communication (Freed et al., 2015; Vogt et al., 2017; Wang et al., 2016; Wiegand-Grefe et. al., 2019). In contrast, healthy family functioning is associated with a family environment with clear and respectful communication, well-defined roles, cohesion, and good affect regulation (Alderfer et al., 2008; Lewandowski et al., 2010). While family dysfunction is associated with diminished HRQoL, the opposite can promote a person's HRQoL (Rüsch et al., 2019).

Family functioning is determined by multiple factors including illness characteristics, psychosocial circumstances and family characteristics. With regard to characteristics of psychopathology, family functioning is influences by symptom type and severity, relapse frequency, suicidal ideation and the severity of impaired functioning (Grandón, Jenaro, & Lemos, 2008a). Adverse psychosocial circumstances such as low socioeconomic status can adversely affect family satisfaction and behavior (Plass-Christl et al., 2017b). Regarding family characteristics, high levels of candid disclosure and high levels of open family communication improve the family's HRQoL, social support and family efficacy beliefs (Rüsch et al., 2019; Bandura, Caprara, Barbaranelli, Regalia, & Scabini, 2011).

2.2.1.4. Mental Health Symptoms in Children and Adolescents

Children of parents with mental illness have an increased risk to develop mental health symptoms due to various genetic and environmental factors (McLaughlin et al., 2012; Plass-Christl et al., 2017a; Weber et. al., 2017a; Wiegand-Grefe et. al., 2011; Wiegand-Grefe et. al., 2009). Mental health problems in the offspring can cause distress and diminished quality of life in their caregiver (Foldemo et al., 2005; Plass-Christl et al., 2017b; Vasilopoulou & Nisbet, 2016). The authors of an Icelandic study with 208 parents of 123 children waiting for psychiatric care concluded that mothers of children with mental disorders have poor quality of life and a high prevalence of mental health deficits. The study did not differentiate between children's psychiatric diagnoses (Guðmundsson & Tómasson, 2002). Other studies reported lower HRQoL of parents caring for children with mental illness and cognitive impairments such as autism spectrum disorder (Khanna et al., 2011) or pervasive developmental disorder (Mugno, Ruta, D'Arrigo, & Mazzone, 2007), Down syndrome and ADHD (Ganjiwale, Ganjiwale, Sharma, & Mishra, 2016). The rates of psychopathology are elevated in parents of children suffering from mental disorders, for example, anxiety disorders (Cooper, Fearn, Willetts, Seabrook, & Parkinson, 2006). The caregiver strain is higher when the children has more severe mental health symptoms (Mendenhall & Mount, 2011). Analyses of qualitative and quantitative data indicate that parents whose children suffer from mental disorders are vulnerable to self-blame, most commonly because they perceive themselves as bad parents who have an ineffective oversight of child's mental health status, who pass on 'bad genes' and who provide children with a negative family environment (Moses, 2010). Parents of children with schizophrenia often report feelings of helplessness, anger, anxiety (Spaniol, Zipple, & Lockwood, 1992). Mothers of children with serious mental illness worry about their children's future due to the child's special need, erratic of worsening of behavior, and long-term consequences (Ambikile & Outwater, 2012). In addition to their own needs to be cared of, parents with mental illness may experience a role change towards becoming caregivers themselves, hence may face increase personal distress and diminished quality of life through caregiving (Foldemo et al., 2005). The prospect of potential mental health impairments in the offspring may also cause distress in parents with mental illness. Research has shown that parents with mental illness even view their children's normal behavior through the lens of their mental illness, and interpret any signs of misbehavior or distress in their children as mental health symptoms (Nicholson et al., 2001). They tend to proxy-report more cases of child mental health symptoms than do their healthy counterparts or their children themselves (Najman et al., 2000). Moreover, parents with mental illness tend to proxy-report lower HRQoL for their children than do the children themselves (Dey, Landolt, & Mohler-Kuo, 2013).

The children's mental health impairments may pose another organizational and emotional challenge for families (Nicholson, Sweeney, & Geller, 1998). Children and adolescents are rarely able to seek and access mental health treatment. They are dependent on their parents' initiative. Parents' motivation and capability to organize appointments with mental health care providers for their children may be partially affected by parents' own symptomatology. For example, parents with depression often experience fatigue, a lack of motivation, feelings of worthlessness and reduced physical and mental activity (American Psychological Association, 2013) that may reduce the likelihood of taking the initiative to seek and access adequate treatment for their children. In addition, parents' own clinical appointments may interfere with those of their offspring's and increase the risk of non-adherence on both sites (Nicholson et al., 2002). Beyond the parental psychopathology, the WHO has identified other universal barriers to care including a lack of resources (e.g., financial, trained personnel and facilities), stigma, lack of transportation, a lack of public knowledge about mental disorders in children and adolescents, and decreased family communication (World Health Organization, 2003). The burden of parents taking care of a mentally ill child is shown by Barkley and colleagues (1992). The authors found that mothers of children with mental disorders were two to three times more likely to be depressed compared to mothers of healthy children (Barkley, Anastopoulos, Guevremont, & Fletcher, 1992). This finding has been supported by a randomized controlled trial conducted in the United States that found that mothers of children with mental illness reported high levels of daily stress due to difficulties in dealing with health care providers and being blamed for their child's mental health symptoms (Scharer et al., 2009). Other factors that contributed to distress in parents of children with mental illness are a lack of support from all involved agencies, lack of information on managing the child's behavior at home, being excluded from treatment decisions of health care providers and social isolation (Koyanagi & Gaines, 1993; Scharer et al., 2009). Family treatments have been recommended because parental distress is associated with the development and maintenance of children's mental health symptoms (Lewis, Dlugokinski, Caputo, & Griffin, 1988; Scharer et al., 2009; Veerman, 1995).

In summary, the children of parents with mental illness commonly experience mental health symptoms (McLaughlin et al., 2012) that reduce their caregivers' quality of life (Foldemo et al., 2005; Plass-Christl et al., 2017b; Vasilopoulou & Nisbet, 2016) and mental health (Scharer et al., 2009).

2.2.1.5. Social Support

Social support can be defined as the perception and actuality of care for a person, the availability of assistance from other people and the integration into a supportive social network (House, 1983). Social support can be informational (the provision of information during stressful situations), instrumental (the provision of tangible goods, services or aids), appraisal (the communication of information that is relevant to self-evaluation rather than problem solving), and emotional support (the provision of caring, empathy, love and trust) (House, 1983). The source of social support has an influence on which type of support is effective (Helgeson, 2003). For example, emotional support is helpful when provided from significant others, whereas informational support is preferred from professionals. The determination of the most functional type of support that is most strongly related to quality of life depends on the kind and severity of the stressor. People exposed to uncontrollable stressors may benefit most from emotional support, whereas informational support may be better suited for controllable ones (Helgeson, 2003).

Numerous studies have shown that social support is an important determinant of quality of life and mental health in adults with mental illness (Caron, Tempier, Mercier, & Leouffre, 1998; Castelein et al., 2008; Maulik, Eaton, & Bradshaw, 2010). Research suggests that people who remain active in various social roles, including being a parent, spouse, citizen, friend and professional, appear to be most satisfied with their lives (Ay-Woan et al., 2006; Eklund, 2001; Kim & Rew, 1994). Similarly, the more time people spend with recreational and social activities the better their quality of life (Ay-Woan et al., 2006; Weeder, 1986). Social support affects quality of life and health outcomes by regulating thoughts, feelings and behavior to promote health, by increasing health-promoting behaviors and by giving an individual a sense of meaning in life (Ay-Woan et al., 2006; Callaghan & Morrissey, 1993; Wang, Wu, & Liu, 2003). A meta-analysis showed that social support was significantly associated with quality of life along with a range of other health outcomes. People who perceived higher levels of social support appeared to show better physical and mental health, more positive role function and behaviors, psychosocial adjustment, coping behavior, health-promoting behavior, self-actualization and quality of life (Wang et al., 2003).

Although particularly parents with mental illness benefit from social support, they sometimes do not have the access to a sufficiently supportive social network. Approximately one third of parents with mental illness perceive the provided social support as insufficient (Wiegand-Grefe et. al., 2012). Psychiatric patients are less satisfied than welfare recipients and the general population with the availability and adequacy of social support, particularly with regard to attachment and child rearing, and thus they show diminished quality of life in the domain personal/intimate relationships (Caron et al., 1998). Bellack and colleagues (2013) proposed that patients with schizophrenia gradually develop isolated lives facilitated through lengthy stays in psychiatric hospitals and impaired social skills. Psychiatric stays remove patients from their normal peer group, reduce social contacts and opportunities to engage in age-appropriate social roles, and limit social interactions to contacts with mental health professionals and other clients with mental illness. In consequence, they have fewer opportunities than healthy pears to acquire and practice social skills, as well as to develop and maintain friendships (Bellack, Mueser, Gingerich, & Agresta, 2013). Furthermore, patients with mental illness may avoid social interaction due to a history of social failure, rejection, criticism (Bellack et al., 2013). Social avoidance has been observed in patients across the psychiatric diagnostic spectrum including schizophrenia (Bellack et al., 2013), avoidant personality disorder (Van den Bos, 2007), substance dependence disorder (Hosseinbor, Ardekani, Bakhshani, & Bakhshani, 2014), depression and anxiety disorders (Fernández-Theoduloz et al., 2019). Health care providers should pay special attention to social support in parents with mental illness as who represent a unique subset of mental health clients that is particularly vulnerable to inadequate social support (Ackerson, 2003).

Peer support is a type of support provided for people with mental health symptoms by other people who experience mental illness themselves (Davidson, Chinman, Sells, & Rowe, 2006). It can promote recovery and well-being in patients with mental disorders irrespective of their diagnosis (Mead, 2003). The sharing of experience along with social proximity can promote the patients' self-efficacy and motivation to achieve recovery, as well as adaptive coping (Lloyd-Evans et al., 2014). This process is facilitated through ongoing upward social comparisons (Festinger, 1954), and reciprocal peer support and empowering peer relationships (Lloyd-Evans et al., 2014). The effective improvement of HRQoL and other factors that are positively associated with quality of life (e.g., self-efficacy, beneficial psychosocial outcomes) through peer support groups has been demonstrated in multiple studies. For example, patients with psychosis who participated in peer support groups as part of a randomized controlled trial reported a higher increase in self-efficacy, social support and quality of life compared to the control group (Castelein et al., 2008). Another randomized controlled trial with more than two hundred patients with severe mental illness compared one-to-one peer support delivered by trained peers in addition to treatment as usual over the course of six months as compared to treatment as usual alone. The intervention group had significantly higher self-efficacy scores at the six month follow up, however no significant differences were found for the patients' quality of life probably because the study had not enough statistical power to detect a true effect (Mahlke et al., 2017). A recent meta-analysis found a positive impact of one-to-one peer support in mental health service on psychosocial outcomes (S. White et al., 2020)

2.2.1.6. Psychosocial Circumstances

Parents suffering from mental illness often face adverse psychosocial challenges like unemployment or custody loss that can diminish their HRQoL (Luciano, Nicholson, & Meara, 2014; Mowbray et al., 2000; Nicholson et al., 2002). It has been estimated that 45-90% of adults with mental illness are unemployed (Rüesch, Graf, Meyer, Rössler, & Hell, 2004). Among parents with mental illness, the rate of unemployment may be even higher as child-rearing may interfere with working schedules and working parents are depend on the availability of child care assistance (Ihle et al., 2001). A naturalistic study conducted in 2007 investigated predictors and course of vocational status, income, and quality of life in 176 people with severe mental illness (Nordt, Müller, Rössler, & Lauber, 2007). The author proposed factors that explain the high rates of unemployment among people with mental illness: low educational achievement, for example due to an early illness onset, the loss of competitive employment after illness onset, and a prolonged period of unemployment due to mental illness that hinders the re-entry to the labor market. Moreover, they found that higher vocational status was predicted by a low number of psychiatric hospitalizations and less severe psychiatric symptoms, a higher educational degree, more years of work experience. Higher income was positively influenced by a higher age of illness onset, competitive employment, higher education, and the absence of a recent hospitalization of a longer duration. Employed patients reported a higher subjective quality of life than unemployed participants, irrespective of the kind of employment. The study demonstrates the need to integrate vocational support early in treatment, especially when people have an early onset of mental illness and have a higher symptom severity (Nordt et al., 2007). Other studies have come to the same conclusion: surveys indicate that unemployed people with mental illness are strongly dissatisfied with not working (Bengtsson-Tops & Hansson, 1999; Harnois & Gabriel, 2000). Employment has been associated with economical security, independence, self-esteem and quality of life (Rüesch et al., 2004). Occupations provide a valued social position and identity (Rüesch et al., 2004). In addition, they are positively related to mental health and quality of life by providing individuals with opportunities for skill development and social connectedness (Aneshensel, Phelan, & Bierman, 1999), as well as self-esteem and structuring of time (Nordt et al., 2007). Research on vocational rehabilitation in people with mental illness indicate that work improves mental health and other aspects of life (Cook & Razzano, 2000)

Custody loss can reduce the HRQoL of parents (Luciano, Nicholson, & Meara, 2014; Mowbray et al., 2000; Nicholson et al., 2002). Results of a representative national survey in the United States of more than 42 000 adults indicate that parents with a serious mental illness are eight times more likely to be in contact with child protective services, and 26 times more likely than mentally healthy parents to have a change in living arrangements. In consequence, parents with mental illness are at greater risk of custody loss compared to parents without mental health symptoms (Kaplan et al., 2019). The rates of custody loss vary with psychopathology. Women with affective disorders are more likely to be primary caregivers of their children than women with psychotic disorders (White et al., 1995). Kaplan and colleagues (2019) emphasized that research rarely disentangles factors besides the parental symptomatology itself that are associated with more frequent contact with child protective services and custody loss. Factors like poverty and unemployment (Rüesch et al., 2004), unaffordable housing, inaccessible health care, community violence, social isolation, substance abuse, and criminal involvement (Brown, Cohen, Johnson, & Salzinger, 1998; Hay & Jones, 1994) are more common among people with mental illness (Mowbray et al., 2000) and facilitate contacts with child protective services (Chaffin, Kelleher, & Hollenberg, 1996). Another study found that one-quarter of their participants didn’t have the mental diagnosis at the time of the first contact with child protective services. Although the sample size of that study was relatively small (36 participants), results highlight the need for policies, programs, and practices to address common risk factors associated with child protective service involvement rather than concentrating efforts solely on parental psychopathology (Ostrow et al., 2020). Studies indicate that most parents fear losing child custody and consequently do not tell care providers probable parenting difficulties (Diaz-Caneja & Johnson, 2004). Consequently, parents hesitate to seek and access clinical treatment or professional support for childcare. Many parents with mental illness who lost custody want to assist in childrearing and regain custody, but find it difficult to maintain contact with their children and are confused about the bureaucratic procedure (Joseph, Joshi, Lewin, & Abrams, 1999; Sands, Koppelman, & Solomon, 2004). Custody loss is associated with diminished health and quality of life in parents (Kenny, Barrington, & Green, 2015; Luciano et al., 2014; Mowbray et al., 2000). A qualitative analyzes of reports from 19 substance-using women revealed that custody loss can even cause signs of posttraumatic stress in parents and increase their structural vulnerability (Kenny et al., 2015). Canadian quantitative analyses of almost 500 sex workers concluded that child removal was associated with deteriorated health in sex workers (Kenny et al., 2019). The results of this study indicate that the deterioration in health is attributable to three interconnected trajectories including the proliferation of mental distress and increased substance use, increased poverty and social displacement in aftermath (Kenny, 2018).

Demographic characteristics such as parental age and gender affect individual perceptions of HRQoL (Janssen & Szende, 2014; Michelson, Bolund, Nilsson, & Brandberg, 2000). The results of population survey across numerous countries consistently indicate that overall HRQoL decreases with increasing age, and that men of all age groups report higher overall HRQoL than women (Janssen & Szende, 2014). Other studies using different HRQoL instruments came to the same conclusion. Age-related decreases in HRQoL may be attributed to decreases in mental and physical health. Gender differences with consistently lower quality of life among women have been observed in many different clinical and nonclinical populations (Michelson et al., 2000; Wijnhoven, Kriegsman, Snoek, Hesselink, & De Haan, 2003). A nationally representative survey conducted in the United States concluded that women’s lower self-reported HRQoL are partly explained by their disadvantaged sociodemographic situation (e.g., lover average income than males, higher proportion of singles). Moreover, they found that gender-associated differences in HRQoL ratings depend to some extent on the HRQoL measure (Cherepanov, Palta, Fryback, & Robert, 2010).

2.3. HRQoL of Children Affected by Parental Mental Illness

About one in five minor children lives with a parent who has a mental disorder (Maybery, & Reupert, 2018). The psychosocial development of COPMI can be impaired when primary caregivers suffer from mental health symptoms. The distress associated with the parental disorder can not only result in emotional and behavioral difficulties in children, it can also impair the children’s overall well-being and life satisfaction by influencing the children’s social relationships, academic achievement, recreational activities and interests (Maybery et. al., 2009; Mowbray & Oyserman, 2003; Siegenthaler, Munder, & Egger, 2012). Families affected by parental mental illness have an increased risk of psychosocial adversities including poverty, housing insecurity, poor family cohesion and conflict (Beardslee, Wright, Gladstone, & Forbes, 2007). Research has consistently shown that HRQoL is reduced in COPMI across different types of parental mental health symptoms (Giannakopoulos et al., 2009) including depression (Dittrich et. al., 2018; Ferro et. al., 2011), bipolar disorder (Goetz et al., 2017) and substance-abuse (Hagen et al., 2019). The most relevant risk and protective factors of HRQoL of COPMI have been identified from previous research and are selected for further consideration. They include parental psychopathology and the parents’ coping behavior, the children’s emotional and behavioral difficulties, family functioning, social support and sociodemographic characteristics.

2.3.1 HRQoL Determinants of COPMI

2.3.1.1. Psychopathology in Parents

Parental psychopathology does not only affect the parent with mental illness but has also implications for all family members. It can create tension, uncertainty, negative emotions and can result in big changes in how family members live their lives. COPMI are more likely than their peers to grow up in unstable home environments and to experience more family conflicts (Kaplan et al., 2019; Pilowsky, Wickramaratne, Nomura, & Weissman, 2006). They face adverse psychosocial outcomes like low socioeconomic status or unemployment significantly more often and report a higher daily strain and more stressful life events (Plass-Christl et al., 2017c). Parental psychopathology can impair parenting skills (Reedtz et al., 2019a) and may result in reduced involvement with the child, insensitivity, hostility, rejection, neglect and potential abuse (Albermann, Wiegand-Grefe, & Winter, 2019; Hosman et al., 2009). For example, a German longitudinal study with 533 participants and their parents found that COPMI had a two to five times higher risk of neglect, physical and sexual abuse than children with healthy parents (Ihle et al., 2001). Impaired parenting can also lead to insecure attachment, emotional dysregulation, negative emotionality and pathological coping strategies, as well as it can enhance the risk of psychopathology in the offspring irrespective of the children's age (Reedtz, Lauritzen, Stover, Freili, & Rognmo, 2019b).

Potentially reduced caring capacities of parents with mental disorders have been observed across different types of disorders. Most studies in this field relate to parental depression. Individuals with depression experience depressed mood most of the day and/or markedly diminished interest or pleasure that interferes with daily life for at least two weeks. Additional symptoms can be fatigue, concentration problems, reduced cognitive and physical activity, withdrawal from social activities, recurrent thoughts of death and feelings of worthlessness (American Psychological Association, 2013). Depressed parents markedly diminished interest in most activities, lack of energy, irritability and depressed mood tend to manifest in negative interactions with their children and in a parenting style characterized by coercion rather than negotiation in conflict situations with the offspring (Conger, Patterson, & Ge, 1995; Ge, Conger, Lorenz, Simons, 1994). Parental depression has further been associated with less child-parent interactions characterized by reduced empathy and verbal communication, emotional availability, parental insecurity, withdrawal and worry, less discipline and a negative family discord (Bronte-Tinkew, Moore, Matthews, & Carrano, 2007; Groen & Petermann, 2011; Leinonen, Solantaus, Punamäki, 2003; Pilowsky et al., 2006; Solantaus-Simula, Punamäki, Beardslee, 2002). Reduced HRQoL of COPMI has been associated with maternal depression both in acute phases and in remission, supposing that impaired parenting skills may emerge during acute phases of depression and persist even after acute symptom remission (Dittrich et. al., 2018; Ferro et al., 2011).

Bipolar disorders are another group of mood disorders causing extreme fluctuations in symptoms of depression and mania, that alternate a person's mood, energy, and ability to function (American Psychological Association, 2013). Manic episodes represent a significant change from usual behavior characterized by an elevated, expansive, or irritable mood for at least one week, and can manifest, for example in increased self-esteem, talkativeness, alertness and risk behavior (American Psychological Association, 2013). Children of parents with bipolar disorder display on average higher rates of lifetime anxiety and mood disorders, reduced quality of life, received less social support and reported less satisfying relationships with peers and parents than children from the general population (Goetz et al., 2017).

Parents with anxiety disorders show an emotional state of fear, worry, or excessive apprehension that interferes with daily activities. Anxiety disorders include for example panic disorders, various phobias, and generalized anxiety disorders. They have a chronic course, although waxing and waning in intensity, and count to the most common mental health symptoms (American Psychological Association, 2013). Anxious parents have been found to share more threat-concerning information with their children (Moore, Whaley, & Sigman, 2004), display lower levels of sensitivity and are less likely to grant their children autonomy (Pape & Collins, 2011). Parental anxiety, possibly resulting in restriction of activities, has been associated with decreased quality of life in COPMI (Williams et al., 2003).

Parents suffering from personality disorders show ensuring, long-term maladaptive and inflexible patterns of behavior, cognition and inner experiences that are exhibited in many contexts and significantly deviate from how the average person in the individual’s culture perceives, thinks, and feels particularly in relation to other people (American Psychological Association, 2013). Personality disorders include paranoid, schizoid, schizotypal, antisocial, borderline, histrionic, narcissistic, avoidant, dependent and obsessive-compulsive personality disorders (American Psychological Association, 2013). It has been suggested that parents with personality disorders were three times more likely than parents without personality disorders to engage in problematic child rearing behavior with inconsistent parental discipline, impaired parental communication and low praise and encouragement for the child (Johnson et al., 2006). Other studies reported intrusive and insensitive child-parent interactions, harsh and frightening parental behavior and abuse (Laulik, Chou, Browne, Allam, 2013). Although maladaptive parenting has been observed across different type of personality disorders (Coley, Carrano, & Lewin-Bizan, 2011; Steele, Townsend, & Grenyer, 2019), research suggests that caring capacities are particularly impaired in parents with borderline and antisocial personality disorders (Johnson et al., 2006). Borderline personality disorder is ‘characterized by a long-standing pattern of instability in mood, interpersonal relationships, and self-image that causes distress or interferes with social and occupational functioning” (Van den Bos, 2007). Children of parents with borderline personality disorder are frequently exposed to their parent’s impulsive behavior, emotional instability in reaction to day-to day events (e.g., intense episodic sadness or irritability), and unstable interpersonal relationships characterized by extremes between idealization and devaluation problems (American Psychological Association, 2013). Children of mothers with borderline personality disorder display significantly more mental health symptoms like emotional dysregulation, suicidal ideation, insecure attachment styles, less stable self-image and poorer general psychopathology than children of parents with depression, ‘cluster C’ personality disorders (e.g., avoidant, dependent and obsessive-compulsive personality disorders), and those of healthy parents (Steele et al., 2019). In consequence, the HRQoL of those underaged children is likely to be reduced, although no study with larger sample sizes has explicitly investigated HRQoL of children with parents affected by personality disorders yet. Parents with antisocial personality disorder show a pervasive pattern of disregard for and violation of the rights of others. Manifestations include deceitfulness, irresponsibility towards the child, impulsivity, aggressiveness, lack of remorse, guilt and empathy (American Psychological Association, 2013; Torry & Billick, 2011). These behaviors can interfere with the children’s development and their ability to form meaningful personal relationships (Torry & Billick, 2011). Children of parents with antisocial personality disorder are at high risk for developing similar behavior patterns, especially when the reduced caring capacities (e.g., abuse, neglect, cold parenting) triggers their genetic liability (Torry & Billick, 2011).

Difficulties in parenting have also been reported for parents with psychotic disorders. Parents suffering from psychotic disorders make incorrect inferences about external reality, even in the face of contrary evidence. Experienced symptoms include delusions, hallucinations, and markedly disorganized speech, thought and behavior (American Psychological Association, 2013; Torry & Billick, 2011). For an Australian national study 195 fathers and 253 mothers of underaged children living with symptoms or a diagnosis of psychosis were surveyed (Campbell et al., 2012). One in four parents with psychotic symptoms showed severely reduced caring capacities in the past year. Nevertheless, the study did also demonstrate that mental illness in primary caregiver does not automatically lead to poor parenting. The majority of parents had still good parenting skills, as rated by the interviewers. They showed resilience in the face of adversity and discrimination, and continued to function well with good chances of recovery (Campbell et al., 2012). A substantial proportion of families in this Australian sample also experienced sociodemographic risk factors like low educational attainment, unemployment and poverty, social isolation as well as stigmatization (Campbell et al., 2012) that are associated with reduced HRQoL of patients and their families (French, Davalos, & Economics, 2011; Hinshaw, 2018; Masuch et al., 2019; Mielck, Reitmeir, Vogelmann, & Leidl, 2013). A review by Bosanac and colleagues (2003) examined the mother-child relationship in patients with schizophrenia. Schizophrenia is a disorder characterized by delusions or hallucinations, incoherent or illogical thoughts, behaviors and linguistic expressions (Van den Bos, 2007). The authors concluded that mother-infant interactions were impaired and were characterized by reduced eye contact, lack of stimulation or difficulty to pick up cues and discordance between mother and infant with lasting cognitive, emotional and behavioral consequences for the child development. (Bosanac, Buist, & Burrows, 2003).

Parents with a substance use disorder display a recurrent use of alcohol and/or other drugs and an inability to control the substance use. An increased amount of time is spend to get, use, or recover from the effects of using the substance, which results in an inability to meet occupational or social obligations within and outside the family setting (American Psychological Association, 2013). Research suggests that children of substance-abusing or substance-dependent parents are at risk of experiencing negative consequences of their parent’s behavior either directly, for example in terms of parental abuse or neglect (Christoffersen & Soothill, 2003) or indirectly, for example in terms of lower socioeconomic status, increased academic and social difficulties or reduced family functioning (Peleg-Oren & Teichman, 2006). A Danish study investigating 84.765 children of alcohol abusers found a high occurrence of parental violence, family separations and foster care placements (Christoffersen & Soothill, 2003). Multiple studies reported reduced quality of life in COPMI due to the adverse consequences of their parent's substance abuse (Christoffersen & Soothill, 2003; Hebbani, Ruben, Selvam, & Srinivasan, 2018).

Children and adolescents under the age of 18 years are particularly vulnerable as they depend on their parents' ability to care for them. They often demonstrate attachment issues (Cunningham et al., 2004; Wan & Green, 2009) and face the loss of or separation from a primary attachment figure (Ihle et al., 2001). Moreover, younger COPMI are at higher risk to develop psychopathology. For example, for one to two years old children parental depression has been associated with impaired cognitive development, behavioral and emotional difficulties, lower IQ scores in late childhood, and higher rates of affective disorders in adolescence (Kowalenko et al., 2012; Reedtz et al., 2019b; Van Doesum, Riksen-Walraven, Hosman, & Hoefnagels, 2008).

Although variations in parenting styles exist among different types of parental mental diagnosis, parenting capacity and the HRQoL of the offspring seems primarily related to symptom severity (e.g., suicidality, psychotic behavior), the frequency and duration of illness (brief, reactive, or endogenous) rather than the diagnosis itself (Reupert, Goodyear, & Maybery, 2012). The association between symptom severity and child HRQoL has, for example, been demonstrated by the results of a Greek national study with 1194 adolescents and 973 parents. The authors found strong positive associations have been found between parents' symptom severity and adolescents' self-reported HRQoL (Giannakopoulos et al., 2009). Self-reported parental mental health was significantly correlated with adolescents' psychological and physiological well-being, moods and emotions, child-parent relationships, school environment and financial resources. In line with this, another study with 72 COPMI under 18 years found that the higher the subjective symptom burden reported by parents the worse the HRQoL of COPMI (Wiegand-Grefe et. al., 2010). Beyond the subjective symptom severity, the duration and chronicity of parental psychopathology is assumed to moderate the effect on the offspring's HRQoL. An extended duration can deplete the children's resources, reduce resilience and lead to the initiation of problematic child behavior associated with long-term consequences (e.g., frequent contact with deviant peers, drug abuse). This assumption would be in line with the delayed-effect hypothesis suggesting that the consequences of multiple family stressors may not be evident until some years later (Forehand, Biggar, & Kotchick, 1998). A meta-analysis on problem behavior in children of chronically ill parents revealed larger effect sizes for internalizing and externalizing problem behavior in children in studies including parents with longer illness duration (Sieh, Oort, Visser-Meily, & Meijer, 2014). COPMI that have experienced multiple stressful situations in the frame of parental mental illness (e.g., depressive episodes with reduced child-parent interactions) due to a longer illness duration are more likely to develop emotional and behavioral difficulties (Cleaver & Unell, 2011).

2.3.1.2. Parental Coping with Mental Illness

Research has demonstrated that the way parents appraise and deal with stressors (e.g., mental illness) has an impact on their own (Peay et al., 2013) as well as their offspring's mental health and quality of life (Jeske, Bullinger, Plas, Petermann, & Wiegand-Grefe, 2009). A German study with 61 COPMI found moderately significant correlations between parental disease management style and the HRQoL of the children. Significant lower quality of life was reported when parents practiced a depressed processing style. Similarly, although non-significant, religiosity and quest for meaning were correlated with lower HRQoL of COPMI. The authors suggested that proactive problem-oriented coping was the best coping style for affected families (Jeske et al., 2009). Adaptive coping strategies can also mitigate the negative outcomes of family burden and to a lesser extent of stigma by association as demonstrated in another study conducted with 503 family members of patients with mental illness (van der Sanden, Pryor, Stutterheim, Kok, Bos, et al., 2016). Most of the family members in this study have already applied adaptive coping strategies in their daily lives to decrease psychological distress and increase quality of life in the short- and long-term. When adaptive coping strategies are not used on own initiative, interventions fostering adaptive coping can improve adjustment and HRQoL of all family members (Fernando et. al., 2018; Sampogna et al., 2018).

Research has demonstrated that psychoeducation is an effective tool to improve adaptive coping not only in patients but also in their relatives (Sampogna et al., 2018). Particularly COPMI benefit from age-appropriate information about their parent's disorder and show better adjustment when they were well-informed (Yamamoto & Keogh, 2018). Meanwhile, psychoeducation has become a common component of interventions for CHIMPS and their families (Reupert et al., 2013). It aims to inform children about their parent's condition, and to reduce feelings of guilt and shame related to parental psychopathology (Reedtz et al., 2019b). Despite the benefits of psychoeducation, parents rarely inform CHIMPS explicitly about their mental illness, as shown by a recent systematic review (Yamamoto & Keogh, 2018). The authors of a 2019 published study with 422 parents with mental illness of 589 minor children reported that the odds that parents had informed their children about the disorder, treatment and hospitalization was linked to the children's age, the child living status, the gender of the mentally ill parent, and his or her primary diagnosis. The older the child was, the higher the chance that the parents educated their child about their condition. The authors proposed that this may be the result of older children being abler to understand the parent's condition and of parents feeling more comfortable talking to mature children. Older children may take the initiative to talk about their parent's condition more often. The likelihood was also higher when the child was living with a single mentally ill parent, probably implying that the mentally ill parent realized that the child can better handle the situation when having sufficient information about their primary caregiver's health status.

When the mother was the parent with a mental illness, the children were more likely to receive information. An explanation proposed by the authors was that children often have closer emotional ties to mothers than to fathers characterized by increased communication. This study did also demonstrate that the chance of disclosing information to the child was higher when the parent's primary diagnosis was severe, probably indicating that the necessity of disclosure increases the higher the negative impact on the child is (Reedtz et al., 2019b). The absence or limited availability of psychoeducation can cause distress, frustration, separation anxiety, concern about the parent, and insecurity due to the unpredictability of their parent's behavior (Pretis & Dimova, 2008; Trondsen, 2012).

2.3.1.3. Mental Health Symptoms in COPMI

Distress associated with mental health symptoms in children reduces HRQoL outcomes (Barkmann et al., 2016; Jonsson et al., 2017). COPMI are more vulnerable to mental health symptoms than children of healthy parents due to both genetic and environmental factors) that interact with one another (McLaughlin et al., 2012; Plass-Christl et al., 2017a; Plass-Christl et al., 2018; Weber et al., 2017a; Wiegand-Grefe et al., 2011; Wiegand-Grefe et al., 2009). In a systematic review Siegenthaler et al. demonstrated that approximately 50 % of COPMI develop mental disorders during childhood or adolescence (Siegenthaler, Munder, & Egger, 2012). Even higher rates have been reported in a longitudinal study showing that the risk of mental illness among COPMI ranges from 41 % up to 77% across the whole diagnostic spectrum of parental mental disorders (Hosman et al., 2009). For example, the incidence of depression or anxiety disorders is elevated by factor two to six among offspring of parents with such a disorder (Biederman et al., 2006; Lieb et. al., 2002) making the parental history of mood and anxiety disorders one of the strongest and most consistent risk factors for the transgenerational transmission of psychopathology (Low et al., 2012). COPMI do not only have an elevated risk of developing the same disorders as their parents but are also more vulnerable for the development of other disorders (Hosman et al., 2009). According to a WHO survey with 51 507 participants showed that the general risk for COPMI to develop any mental illness was 1.8 to 2.9 times higher compared with the general population if one parent was affected. When both parents were affected, the risk raised to 2.2 to 4.6 (McLaughlin et al., 2012). Children who suffer from mental health symptoms commonly experience a lack of control, choice and autonomy, low self-esteem and confidence, a sense of hopelessness and exclusion from society (Mattejat & Remschmidt, 2008). Those negative feelings diminish an individual's HRQoL (Jonsson et al., 2017).

Hosman et al. (2009) proposed a developmental model of transgenerational transmission of psychopathology displayed in *Figure 3*. Based on previous literature Hosman and colleagues concluded that both disorder-specific (e.g., genetic factors, pathological coping styles, parental modelling behavior) and common factors (e.g., poverty, family conflict, and parentification) are responsible for the elevated risk of psychopathology in COPMI. Protective factors (e.g., social support, the children's problem-solving skills) buffer the negative impact of risk factors. The model acknowledges both mothers and fathers and is applicable across a range of diagnostic disorders. Multiple interacting systems of influence are included (e.g., mentally ill parent, family, child, social environment) to which specific risk factors and protective factors are linked including genetics, parental influences, child-parent interactions, the family and social environment. A developmental perspective considers age-related risk factors and developmental tasks.

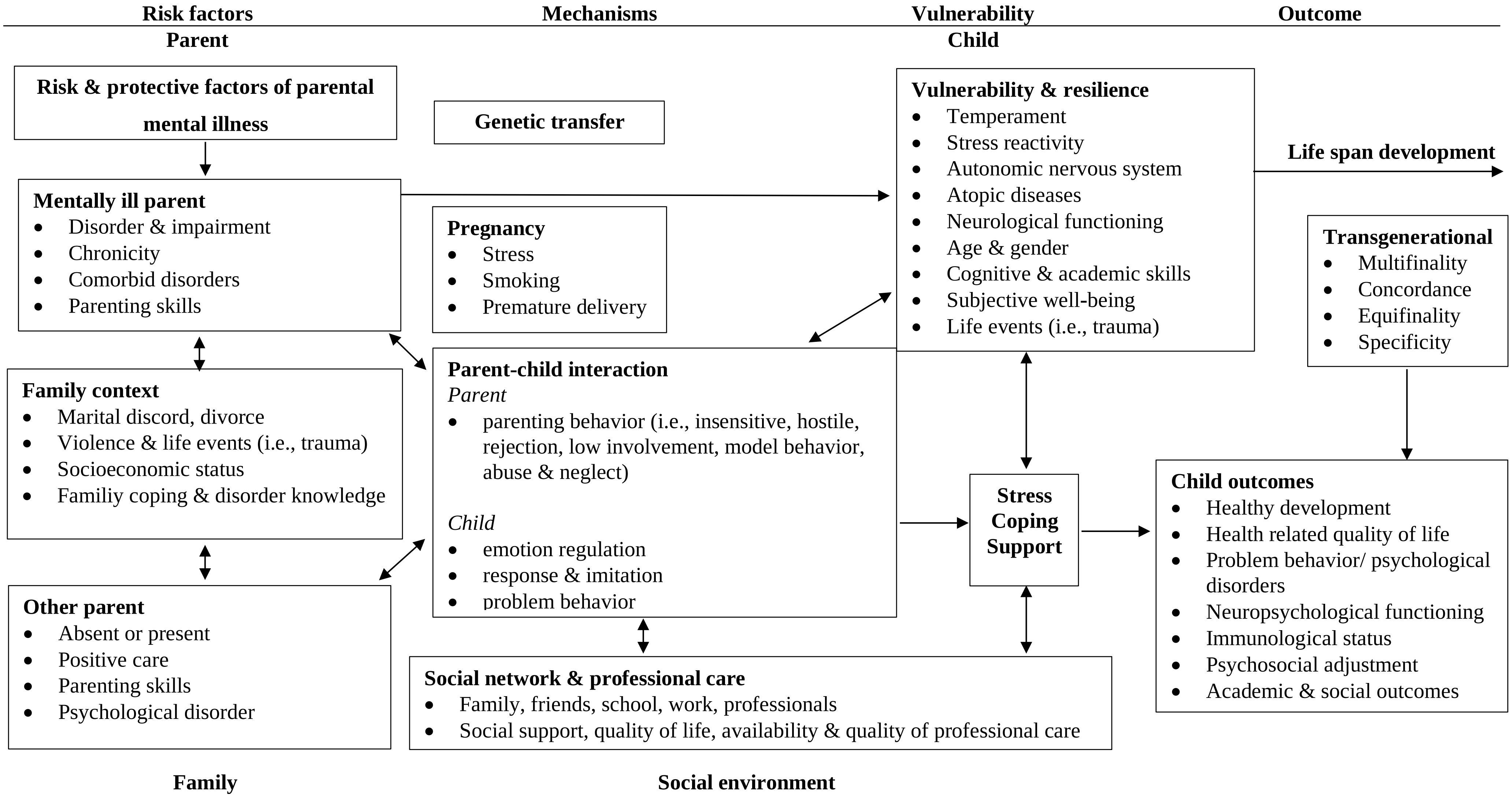

Figure 3. Transgenerational transmission of psychopathology by Hosman et al. (2009)

Parent-related factors include characteristics of parental psychopathology, risk factors during pregnancy, as well as parenting competence and child-parent interaction. The authors propose that the risk of child mental health symptoms is higher when children are exposed to recurrent and chronic parental disorders, to the presence of multiple disorders (comorbidity), when both parents are affected and when the age of onset of parental mental disorder occurs in early stages of the child’s life span. Their notion has been supported by other research showing that certain characteristics of the parents’ psychopathology like parents’ subjective symptom burden, comorbid psychiatric diagnoses (van Santvoort et al., 2015), symptoms severity (Brennan et al., 2000), and duration of illness (Reedtz et al., 2019a) decrease the children’s mental health. In addition, there is evidence that the exposure to prenatal stress due to the parental psychopathology can result in a general susceptibility to psychopathology in children (Huizink, Mulder, & Buitelaar, 2004). A study with 120 healthy 2-years old children and their parents found that higher prenatal maternal anxiety was associated with increased negative temperament in the children. The latter could not be explained by postnatal maternal anxiety, demographic, or obstetric factors (Blair, Glynn, Sandman, & Davis, 2011). Besides psychopathology during pregnancy, there are other neonatal risks that are associated with an increased risk for later psychopathology in children. They are related to the prenatal environment and include, for example, maternal physical health, maternal use of prescribed and non-prescribed drugs (Behnke & Eyler, 1993), and to intrapartum events like birth difficulties and perinatal hypoxia (Giannopoulou, Pagida, Briana, & Panayotacopoulou, 2018). Further parent-related factors that merit consideration in the transgenerational transmission of mental disorders are parenting competence and the quantity and quality of child-parent interactions. (Hosman et al., 2009). Adverse child-parent interactions and parenting skills have been found across different types of disorders (e.g., Steele, Townsend, & Grenyer, 2019; Groen & Petermann, 2011; Bronte-Tinkew, Moore, Matthews, & Carrano, 2007). Particularly punitive parenting involving harsh and often erratic disciplinary actions and lack of emotional warmth impairs the children’s well-being and facilitate the development of both internalizing (e.g., depressive symptoms) and externalizing (e.g., antisocial behavior, alcohol abuse, aggression) symptoms in children (Leinonen et al., 2003). COPMI are especially vulnerable when they experience poor parenting during the early life years, when parents provide children with pathological mode behavior and coping styles over a prolonged period, and when they trigger dysregulated emotion patterns, negative emotionality, insecure attachment, decreased self-esteem and self-efficacy beliefs in children (Hosman et al., 2009). During the school years, the quality of parenting is an important predictor of the children’s school achievement, peer relations and adjustment (Maccoby, 1984).

Family-related factors can mediate the impact of parental psychopathology on a child (Ashman, Dawson, & Panagiotides, 2008; Avenevoli & Merikangas, 2006; Leinonen et al., 2003). Familial risk factors include family conflicts, marital discord and divorce, violence and traumatic life events, low socioeconomic status, adverse family coping and insufficient knowledge about the parental disorder (Hosman et al., 2009). Moreover, instable family living conditions (e.g., many house moves), difficult family constellations and a high parental strain in day-to-day life increase the children's risk of mental illness (Plass-Christl et al., 2017c).

The presence of a healthy caregiver in addition to the parent with mental illness can serve as a protective factor for children's mental health and psychosocial development (Chang, Halpern, & Kaufman, 2007; McLaughlin et al., 2012). Studies have shown that healthy caregivers tend to adjust their parenting to compensate for their partner's psychopathology and for their partners' decreased involvement with the children (Harvey, Stoessel, & Herbert, 2011; Kelley, Bravo, Braitman, Price, & White, 2018; Zaslow, 1985). For example, fathers respond to children's misbehaviors more rationally when their wives report higher levels of anxiety (Harvey et al., 2011). Similarly, mothers increase their interactions with the child when their moderately depressed partners showed reduced parenting behaviors (Zaslow, 1985). Many children have care responsibilities and provide critical crisis support (e.g., during episodes of self-harm or psychosis) that exceed their emotional and cognitive maturity (Aldridge, 2006). Healthy caregivers can carry over those tasks thereby reducing the psychological burden of children. The presence of a healthy partner can also support parents with mental illness and decrease their symptoms. A study with 3700 participants showed that married parents with mental illness self-reported less mental health symptoms than their single peers (DeKlyen et. al., 2006). Despite the benefits of a supportive healthy parent or partner for the families well-being, single parenthood is prevalent among people with mental illness (Mowbray et al., 2000; White et al., 1995).

The major *child-related risk factors* identified by Hosman, van Doesum, and van Santvoort's (2009) include a difficult temperament, behavioral inhibition, negative emotionality, stress reactivity, insecure attachment, negative self-esteem, poor cognitive and social skills, lack of knowledge about the parental disorder, parentification and self-blame, traumatic life events, and physical health constraints. They operate as mediators between the parents' and the children's psychopathology (Hosman et al., 2009). Demographic factors like a young age at the onset of parental disorder have also been identified as risk factors predicting child psychopathology, possibly due to a stronger impact of genetic factors in early stages of the children's life span (Hosman et al., 2009). The children's gender has played a moderating role in numerous studies and is particularly predictive of externalizing versus internalizing mental health symptoms, whereas the latter is more prevalent in females (Hosman et al., 2009). The more recent BELLA study examined data of more than 320 children and adolescents aged 11-17 who had a parent with mental health problems. The analyses of longitudinal data indicated no direct age and gender effects but a significant interaction effects showing that female compared to male COPMI show increased mental health problems with increasing age. The authors suggested the implementation of support programs that consider that female COPMI with growing age may have a high risk of internalizing symptoms (Plass-Christl et al., 2018). Protective child-related factors mainly refer to the opposite of risk factors. Thus, the children's resilience is i.a. promoted by sufficient knowledge about the parental disorder, positive emotionality, and cognitive and social competence (Hosman et al., 2009).

Factors related to the social environment are established in various social settings like school, friendships, neighborhood and professional care. Social relationships have both immediate and long-term cumulative effects on mental and physical health (Umberson, Karas Montez, 2010). The social environment can provide cognitive, emotional and practical support thereby serving as a protective factor for the child's mental health and moderating the effect of parental psychopathology (Masten & Coatsworth, 1998). Children benefit from stable relationships with both trusted non-familial adults like educational staff and familial adults in the child or parent's social network and friends (Fudge & Mason, 2004; , Ling, Szakacs, & Reupert, 2005). On the contrary, it can increase the risk of mental health symptoms when COPMI experience social isolation, stigmatization (by association) and discrimination. Socially withdrawn and rejected children and adolescents are simultaneously and predictively at risk for a wide range of negative adjustment outcomes, including socioemotional difficulties (e.g., internalizing and/or externalizing symptoms, low self-esteem), peer difficulties (e.g., rejection, victimization, poor friendship quality), and academic difficulties (e.g., school absenteeism, low academic achievement, impaired relationship with teachers) (Rubin, Coplan, & Bowker, 2009). Experiences of stigmatization, discrimination or rejection adversely affect the offspring's mental health and quality of life (Hinshaw, 2018; Lundberg, Hansson, Wentz, & Björkman, 2008; Mielck et al., 2013). They are associated with emotional distress (Rüsch, Corrigan, Wassel, et al., 2009), low self-efficacy and coping abilities (Kleim et al., 2008), anxiety (Norman, Windell, Lynch, & Manchanda, 2011), depressive symptoms, and decreased self-esteem (Haverfield & Theiss, 2016; Johnson & Stone, 2009).

To conclude, COPMI have a significant risk of mental illness for a number of genetic and environmental reasons (Dey, Mohler-Kuo, & Landolt, 2012; Hosman et al., 2009; Weber, Jud, Landolt, & Goldbeck, 2017b), which is associated with lower child HRQoL outcomes (Barkmann et al., 2016; Jonsson et al., 2017). Risk and protective factors associated with child mental health include child, parent, family and social aspects.

2.3.1.4. Family Functioning

An intact family environment is particularly important for children, as family members are children's main socialization agents. They provide the children with communication and relationship skills that will affect the children's interpersonal relationships throughout their lifetime (Oetzel & Ting-Toomey, 2006), as well as with various kinds of social support (Collins & Laursen, 2004). Research suggests a significant relationship between family functioning and HRQoL of pediatric populations (Goldstein et al., 2008; Herzer, Denson, Baldassano, Hommel, & hepatology, 2011; Weissberg-Benchell et al., 2009). Children and adolescents with poor social support from family members reported significantly lower HRQoL and mental health compared to strongly supported children (Ravens-Sieberer, 2006).

Previous research has demonstrated that family functioning is frequently impaired in families with a parent with mental illness across different psychiatric diagnoses. Maternal depression has been associated with family discord, marital conflicts and divorce, and it increases the likelihood of depression in family members (Letourneau, Tramonte, & Willms, 2013). Families with bipolar parents experienced more familial conflicts, lower levels of expressiveness, organization and intellectual-cultural orientation (Barron et al., 2014) as well as lower family cohesion (Freed et al., 2015). Patients with anxiety disorders showed impaired family functioning, intrafamilial communication, affective responsiveness, and affective involvement when compared to healthy controls. The authors suggested that family dysfunction in anxious patients may result from a tendency to hide information from family members and a patient's fear or difficulty to show interest in other things or people (Wang et al., 2016). Findings from cross-sectional studies demonstrate that adults with borderline personality disorder had a reduced family functioning compared to both normative and clinical controls, manifested in reported low empathy and conflicting family relationships (Allen et al., 2005), contradictory family communication patterns (Guttman & Laporte, 2000), and lack of perceived protection by mothers (Lyons-Ruth, Choi-Kain, Pechtel, Bertha, & Gunderson, 2011; Infurna et al. 2016). The family burden of families of patients with psychosis has also been found to be high in different life domains, expressed by a reduction of subjective health, restrictions daily routine, social contact and leisure time, as well as occupational, coping and mental health symptoms reported by caregivers and family members (Koutra, Vgontzas, Lionis, & Triliva, 2014). The extent of family burden has been determined by clinical characteristics like symptom type and severity, a higher relapse frequency and the severity of impaired functioning (Grandón, Jenaro, & Lemos, 2008b).

Family functioning is an important determinant of the children's HRQoL (Ferro et al., 2011; Kessler et al., 2010; Knappe et al., 2009). Family dysfunction bears an elevated risk of cognitive, emotional, and behavioral symptoms in children (Becona et al., 2012; Boricevic Marsanic, Margetic, Zecevic, & Herceg, 2014; Freed et al., 2015; Kessler et al., 2010). According to an international representative World Mental Health Survey with 51 945 adult participants, retrospectively reported childhood adversities associated with family dysfunction (e.g., parental mental illness, child abuse, neglect) were the strongest predictor of mental disorders across the life course, accounting for 29.8% of all disorders across 21 countries (Kessler et al., 2010). Family functioning has frequently been acknowledged as a third variable explaining the relationship between parental mental health and the offspring's mental health. A mediation has been found with regard to the intergenerational transmission of childhood conduct problems (Raudino, Fergusson, Woodward, & Horwood, 2013), depressive and anxiety symptoms (Fossion et al., 2015; Park et al., 2015), and externalizing symptoms in adolescents (Van Loon, Van de Ven, Van Doesum, Witteman, & Hosman, 2014). The cognitive, emotional, and behavioral functioning of younger age groups may be particularly affected by a dysfunctional family system as family members are their primary source of social support. (Collins & Laursen, 2004). In line with this assumption are the results of a study of 117 children of parents with bipolar disorder. Younger offspring was more prone to internalizing symptoms than their older peers when family cohesion was low, suggesting a higher risk of psychopathology for younger children in dysfunctional families (Freed et al., 2015). In addition to an elevated risk of psychopathology, family dysfunction has also been associated with higher persistence of mental disorders. A meta-analysis revealed the importance of family functioning on the development, maintenance and treatment of anxiety and depression in childhood (McLeod, Wood, & Weisz, 2007). In compliance with these results, a longitudinal German cohort study with 1395 adolescents and their parents demonstrated that family dysfunction alone and in interaction with parental psychopathology predicted higher social phobia persistence. The sample was followed for almost 10 years (Knappe et al., 2009).

On the positive side, high functioning families with frequent and positive child-parent interactions and low familial conflicts exert a positive impact on the family members' well-being (Ferro et al., 2011; Jozefiak & Wallander, 2016), strengthen the children's resilience and may compensate for the negative effects of parental psychopathology (Olsson et al., 2003). Healthy family functioning compromises clear communication, well-defined roles, cohesion, and good affect regulation (Lewandowski et al., 2010). It promotes positive health outcomes in COPMI and mediates the relationship between parental mental disorder and children's HRQoL as well as the children's mental health. A prospective study conducted with 339 mother-child dyads demonstrated that children of mothers with depressive symptoms have poorer HRQoL over time, but this relationship was moderated by family resources and partially mediated by family functioning and demands. The authors concluded that family-centered approaches of health care promote more positive health and HRQoL outcomes in COPMI (Ferro et al., 2011). The same conclusion was drawn by researchers that found evidence for the mediating role of perceived family functioning and self-esteem of the relationship between family adversity and symptom severity of social anxiety disorder in a sample of 5607 adolescents (Yen et. al., 2013). Similarly, a Canadian study with 2346 adolescents aged 13 to 16 years found that the association between parental psychological distress and internalizing in these children was mediated by adolescent self-esteem, parental emotional support and extra familial social support. For externalizing disorders, these variables had an independent effect. The authors stressed the importance of a healthy and positive family environment as a necessary condition for psychosocial adjustment in adolescence (Roustit, Campoy, Chaix, & Chauvin, 2010). The emotional and practical support by family members strengthens the resilience of children and improves coping skills (Olsson, Bond, Burns, Vella-Brodrick, & Sawyer, 2003). Family functioning also has significant indirect effects on HRQoL through health-promoting behaviors encouraged by family members (Ali & Malik, 2015). Several studies suggest the implementation of family-centered interventions focusing on psychoeducation and communication skills to improve familial organization, expressiveness and conflict management, and to intervene at the family level in order to promote mental health and quality of life in COPMI (Ferro et al., 2011; Kessler et al., 2010; Knappe et al., 2009).

2.3.1.5. Social Support

COPMI grow up in various social networks including family, school, peers, neighborhoods and community. Each social network can provide COPMI with varying amounts and different types of support. Research on the association between social support and children's well-being did not receive much attention until the 1980s, although it has been suggested that they need even more social support than adults do (Chu, Saucier, & Hafner, 2010). Social support is an important predictor of mental health in children and adolescents (Azmitia, Cooper, & Brown, 2009; Hombrados-Mendieta, Gomez-Jacinto, Dominguez-Fuentes, Garcia-Leiva, & Castro-Travé, 2012). It offers children and adolescents positive emotions, a sense of self-worth, predictability in life, and promotes their resilience by reinforcing self-esteem, self-efficacy and problem solving skills (Chu, Saucier, & Hafner, 2010). High social support reduces the negative impact of distress and allows children to maintain good functioning, whereas low social support reduces HRQoL and facilitate the development of sub-clinical and clinical symptoms (Chu, Saucier, & Hafner, 2010; Cohen & Wills, 1985; Raffaelli et al., 2013). All in all, research supports the 'stress-buffering hypothesis" stating that specific factors, including social support, can lessen the association between stress and negative outcomes (Cohen & Wills, 1985; Raffaelli et al., 2013).

COPMI frequently experience a reduction in family functioning and in the availability of social support from mentally parents, stressing the importance of the formation and maintenance of social connections outside the family. However, the parental mental disorder may also restrict social support from other social networks. It has been estimated that about one third of families with a parent with mental illness perceive the provided social support as insufficient (Wiegand-Grefe, 2012). Research findings indicate that COPMI from conflict-ridden families were viewed less favorably by their peers and had difficulties to find and maintain friends (Criss, Pettit, Bates, Dodge, & Lapp, 2002). Insufficient social support for COPMI may be due to adverse psychosocial outcomes associated with the parental psychopathology (e.g., unemployment, low educational attainment), an elevated likelihood of compromised social skills interfering with the development and maintenance of social connections, as well as stigmatization by association.

Parents with mental disorders and their families frequently experience adverse psychosocial outcomes (Campbell et al., 2012), which can decrease the availability of social support for COPMI (Glaeser, Laibson, & Sacerdote, 2002) and reduce their HRQoL (Barkmann et al., 2016; Bot, Den Bouter, & Adriaanse, 2011; Ellert, Brettschneider, & Ravens-Sieberer, 2014). For example, a substantial proportion of parents with psychotic symptoms face low educational attainment, unemployment, poverty, and social isolation, as found in an Australian national survey conducted with 1825 patients (Campbell et al., 2012). Those factors are related to social relationships and social support. Low educational attainment, for example, can decrease the availability of social support, because it interferes with the acquaintance of social, language, and communication skills learned in academic contexts that facilitate social interactions (Glaeser et al., 2002). Findings are less clear regarding whether low socioeconomic status reduces social support. A literature review came to the conclusion that childhood and adult socioeconomic status were relevant predictors of social support. However, the reviewed studies varied in their operational definition of socioeconomic status and social support, as well as in the constitution of their samples, making the interpretation of this conclusion difficult (Aneshensel, Phelan, & Bierman, 2013). The impact of socioeconomic status on social support may depend on the type of social support that is considered. For example, studies of adolescents and young adults found socioeconomic status to be related to family support but not to support from peers (Gayman, Turner, & Cui, 2008).

Findings indicate that social competence has an impact on the availability of social support, thereby predicting resilience and HRQoL of COPMI. ‘Social competence refers to the social, emotional, cognitive skills and behaviors that children need for successful social adaptation” (Omkarappa, Rentala, & Nattala, 2019). It encompasses the ability to complete tasks, manage responsibilities and effective skills for handling social and emotional experiences (Jones, Greenberg, & Crowley, 2015). Research indicates that social competence in early childhood significantly predicts future outcomes two decades later across major life domains including education, employment, substance use, and mental health (Jones et al., 2015). The predictive power of teacher-measured prosocial skills in the study by Jones et al. (2015) was independent of socioeconomic status, family risk status, neighborhood quality and children’s behavioral traits and early academic ability. Social competent children behave prosocial, have better relationships with peers and teachers and are likely to possess about better social support in challenging situations (Franco, Beja, Candeias, & Santos, 2017). Several studies have reported reduced social competence in COPMI across a range of parental mental diagnoses, including children of depressed parents (Childs, Schneider, & Dula, 2001; Maughan, Cicchetti, Toth, & Rogosch, 2007) and children of alcoholics (Eiden, Colder, Edwards, & Leonard, 2009; Omkarappa et al., 2019). Compromised social skills may result either from exposure to the parental mental illness or may develop independently. For example, children of alcoholics are frequently exposed to high levels of interpersonal conflict, domestic violence, parental inadequacy, abuse and negligence, which interfere with the development of social competence (Omkarappa et al., 2019). Studies with COPMI have found that compromised social skills predispose those children to develop mental disorders (Hosman et al., 2009) and decrease the availability of social support as they have difficulties to maintain satisfactory peer relationships (Childs et al., 2001). COPMI with reduced social competence can profit from social and emotional skills training in school that can not only have positive long-term effects on academic achievement but can also result in increased acceptance by peers and adults (Márquez, Martín, & Brackett, 2006).

The acceptance by peers and society can also be diminished due to stigmatization, which reduces HRQoL of family members of mentally ill patients (Hinshaw, 2018; Zhang et al., 2018). It has been suggested that people with mental disorders are stigmatized more severely than those with other health conditions (Corrigan, Buchholz, Michaels, & McKenzie, 2016). Stigma by association affects relatives of mental health patients, too. They can be devalued, avoided or socially excluded because they are somehow connected to a person with a stigmatized identity (Bos, Pryor, Reeder, & Stutterheim, 2013). Parents with mental illness can be stigmatized as having reduced caring capacities or being violent and their children as pitiful or contaminated leading to discrimination regarding child custody arrangements, housing or employment opportunities as well as to overpathologizing by researchers and clinicians (Larson & Corrigan, 2008; Reupert & Maybery, 2016). Research suggests that stigmatization of COPMI reduces acceptance of peers and friends and undermines success at school or extra-curricular activities (Hinshaw, & Cicchetti, 2000; Swords, Heary, & Hennessy, 2011), thereby lowering the chances of extra familial social support. Furthermore, stigmatization by association and discrimination has been associated with greater psychological distress and family burden as well as reduced quality of life in family members of mental health patients (Hinshaw, 2018; Rüsch, Corrigan, Powell, et al., 2009; van der Sanden, Pryor, Stutterheim, Kok, Bos, et al., 2016). Internalized stigma refers to the internalization and acceptance of stigmatization by others. Individuals with internalized or self-stigma ‘endorse stereotypes, anticipate social rejection, consider stereotypes to be self-relevant, and believe they are devalued members of society” (Picco et al., 2016).

In summary, the availability of social support for COPMI can be compromised for a number of reasons. As social support is a relevant predictor of the majority of HRQoL dimensions (Giannakopoulos et al., 2009), it should be made available for COPMI in need. One common intervention for COPMI are peer support programs that connect children with peers with similar life circumstances (Foster, Lewis, & McCloughen, 2014; Reupert & Maybery, 2009). Peer support groups aim to promote resilience and well-being in COPMI by fostering mutual support, psychoeducation and coping skills. Because COPMI fear stigmatization by society, many children do not talk about their familial situation (Hinshaw, 2004) which results in feelings of social isolation (Mordoch & Hall, 2008). A recent randomized controlled trial (RCT) investigating the effectiveness of Dutch support groups for children aged 8-12 years found a significant decrease in negative thoughts, emotional and behavioral difficulties compared to a control condition. In addition, participants had significantly more peer connections after the interventions (van Santvoort, Hosman, van Doesum, & Janssens, 2014). Another RCT with older children aged 12-18 years reported significant improvements in life gratification, psychoeducation and depression (Fraser, & Pakenham, 2008). Studies evaluating the effectiveness of peer support groups with pre-post designs found improvement in children’s self-esteem, problem-focused coping, family relationships (Goodyear, Cuff, Maybery, & Reupert, 2009; Hayman, 2009), a decrease in depressed mood and perception of social stigma (Hargreaves, Bond, O'Brien, Forer, & Davies, 2008), improved psychoeducation and life skills (Pitman & Matthey, 2004) as well as pro-social actions and life fulfillment (Morson, Best, de Bondt, Jessop, & Meddick, 2009). Similar improvements in social support and HRQoL have been reported for interventions targeting the whole family (Wiegand-Grefe et al., 2012). The predecessor study of the present randomized controlled multicenter CHIMPS project had a pre-post design with a waiting-list control group. The pilot trial showed that the manualized CHIMPS intervention improved children's social support, but also mental health and quality of life along with family relationships and parents' coping strategies (Wiegand-Grefe et. al., 2016; Wiegand-Grefe et. al., 2015; Wiegand-Grefe et. al., 2013; Wiegand-Grefe, Halverscheid, & Plass, 2011; Wiegand-Grefe et al., 2012).

2.3.1.6. Sociodemographic Variables

Research has identified multiple relevant sociodemographic predictors of HRQoL of children, which relate to both children and their family. Whereas some of them (e.g., the children's age and sex) are independent of parental psychopathology, others may at least be partially related to it (e.g., socioeconomic status).

Child-Related Sociodemographic Variables. The most consistent results regarding child-related demographics that influence HRQoL perceptions have been reported for the child's age and sex. Younger children tend to report higher HRQoL than their older peers. Results of a cross-cultural European survey researching HRQoL with the KIDSCREEN-27 in a sample of 22 827 children and adolescents showed that children aged 8-11 years scored higher than adolescents aged 12-18 years in all KIDSCREEN-27 dimensions, but especially in the dimensions 'Physical Well-Being" and 'Mental health (Ravens-Sieberer et al., 2007). Similar age-related decreases in life satisfaction have been reported for both genders in other studies investigating the general population (Bisegger, Cloetta, Von Bisegger, Abel, & Ravens-Sieberer, 2005; Giannakopoulos et al., 2009; Goldbeck, Schmitz, Besier, Herschbach, & Henrich, 2007; Hagen et al., 2019; Meade & Dowswell, 2015; Michel, Bisegger, Fuhr, & Abel, 2009).

Research has consistently demonstrated gender-related differences in HRQoL. Males tend to report higher HRQoL than females, particularly during adolescence. The results of the European KIDSCREEN study conducted by Ravens-Sieberer et al. (2007) demonstrated that boys reported higher HRQoL of the dimensions 'Physical-Well-Being', 'Mental health' and 'Parents Relation & Autonomy'. On the other hand, girls aged 8 to 11 years had higher values on the subscale 'School Environment' and adolescent girls between 12 and 18 years scored slightly higher than boys in the 'Social Support & Peers' dimension. Results are in line with other studies suggesting that females have a poorer perception of their own HRQoL and report a higher frequency of somatic symptoms than boys at all ages (Bisegger et al., 2005; Cavallo et al., 2006; Ravens-Sieberer et al., 2007). Gender differences in HRQoL tend to emerge around the ages of 11 to 14 years (Kristine Amlund Hagen, Hilsen, Kallander, & Ruud, 2018). The risk of poor self-perceived HRQoL increases for girls with each year of adolescence, as demonstrated by a significant interaction effect between age and gender for perceived health and for reported symptoms in females with respect to males in a representative national sample constituted of more than 160 000 subjects (Cavallo et al., 2006). It has been suggested that the reported decreased in HRQoL with age by girls can be ascribed to age-specific challenges such as menarche or a tendency for girls to report more depressive symptoms around this age (Hagen et al., 2018).

Parent-Related Sociodemographic Variables. Only a few studies have directly investigated the effects of parent-related sociodemographic variables on HRQoL of COPMI. The most salient family-related predictors appear to be socioeconomic status. Socioeconomic status is defined by a person's social and economic standing in relation to others. It is commonly measured by a combination of education, income and occupation. In a recently conducted study, families of parent(s) with mental illness frequently faced adverse psychosocial outcomes like low socioeconomic status or unemployment significantly more often than healthy parents. They did also report a higher daily strain and more stressful life events in consequence (Plass-Christl et al., 2017). Children and adolescents of lower socioeconomic status tend to report lower HRQoL than their wealthy peers. Results indicate that child HRQoL was reduced when children had worse school environments due to a lower socioeconomic status, and had low-educated parents with a small household income and low levels of social capital (Bastardo & Mendoza, 2016; Ellert et al., 2014; Gururatana, Baker, Robinson, 2014; Mirmoghtadaee et al., 2016; Sfreddo, Moreira, Nicolau, Ortiz, & Ardenghi, 2019; Tomazoni et al., 2014; Tsakos et al., 2017). The results demonstrate that socioeconomic status is a relevant predictor of health and life satisfaction in children and adolescents. It determines the access to material and structural resources such as food, education and later employment, shelter, health care services and amenities (Sfreddo et al., 2019). It has been suggested that individuals from lower socioeconomic status report reduced health due to an accumulation of negative exposures, limited material resources and health care access, as well as adverse psychological conditions like higher levels of anxiety, poorer coping skills and social support (Sfreddo et al., 2019). Reduced health, in turn, has a negative impact on an individual's HRQoL.

2.3.2. Child-Parent Reliability Regarding Child HRQoL Measures

There has been a rapid increase in the past 20 years in the development and utilization of child HRQoL measures that rely on the children's self-reports (Varni, 2003). The assessment of HRQoL provides useful information that can help to optimize therapeutic strategies, identify effective treatments or ones to improve, aid clinical decision making and decision making on resource allocation within health care, as well as it may contribute to health care quality assurance (De Civita et al., 2005; Wallander & Koot, 2016). Furthermore, the comprehensive assessment of children's HRQoL may is useful for the evaluation of policy decisions and for the identification of health disparities and tracking population trends (Varni, Burwinkle, Seid, & Skarr, 2003). It has been suggested that HRQoL assessments should cover a multidimensional perspective (Cummins, Lau, & Stokes, 2004; Wallander & Koot, 2016; Warne, Snyder, & Gådin, 2014).

Selecting the appropriate instrument to evaluate HRQoL of childhood can be challenging, as multiple HRQoL of instruments for children measure different aspects of HRQoL and each having its own advantages and disadvantages. Today, at least 30 HRQoL generic HRQoL instruments for children are available (Wallander & Koot, 2016). Two well-established generic HRQoL instrument that currently receive the most attention and possess about both child-self report and parent-proxy report versions include the Pediatric Quality of Live Inventory (PedsQL^{TM}) (Varni, Seid, & Rode, 1999) for children from the age of 5 years and the KIDSCREEN (Ravens-Sieberer, 2006) for children and adolescents from the age of 8 years. Generic measures generate health profiles based on multiple domains and can be administered to various clinical and non-clinical populations. On contrary, disease-specific measures are used to investigating specific health problems, symptoms, treatment experiences and responsiveness (Wallander & Koot, 2016). They can only be applied in the corresponding patient group. The selection of generic versus specific instruments depends on the research objectives, and the patients' characteristics. Among the strengths of the generic HRQoL assessment is its broad application in multiple child populations (Simon, Chan, & Forrest, 2008). Ideally, HRQoL assessment tools should provide both overall HRQoL profile scores and domain-specific scores. The decision on appropriate HRQoL measures should not only consider the advantages and disadvantages of generic versus disease-specific instruments but take also into account their psychometric properties. Various types of reliability (e.g., internal consistency, test-retest reliability) and validity (e.g., construct and content validity) should be established in several studies to ensure that the questionnaire is accurate over time and measures what it intends to measure. In addition, Lin et al. (2013) proposed that appropriate instruments should fit to both patient and situation, taking into account the patient's social and material contexts. Furthermore, as HRQoL is a multidimensional construct, assessment tools should combine indicators of objective functioning and subjective well-being. The authors recommend that HRQoL ratings should be primarily obtained directly from patients as interrater reliability between patients' self-reports and proxy reports may vary depending on the raters' characteristics and relationships as well as the HRQoL domain that is being assessed (Lin, Lin, & Fan, 2013). Pediatric research instruments should cover the major HRQoL domains such as physical functioning, emotional and cognitive functioning, general behavior (social, school, home), life perspectives and expectations, health perceptions, coping abilities, pain and discomfort, and autonomy (Mabugu, Revill, & van den Berg, 2013). It is recommended that appropriate HRQoL tools should be age sensitive to reflect developmental milestones (e.g., in the cognitive, motor, language, and social domains) that influence pediatric quality of life (Mabugu et al., 2013).

Self-reports are considered the 'gold standard' with regard to the assessment of subjective views on health and well-being (Ravens-Sieberer, 2006)**.** The shift towards patient-reported outcomes in clinical trials emphasizes the value of pediatric self-report assessments as efficacy outcomes in clinical research (Health et al., 2006). Although self-reports by children are valuable sources of information, parent proxy-reports are often used as a replacement (Upton et al., 2008). This practice has been justified by the assumption that younger children lack sufficient cognitive and linguistic abilities to understand and interpret HRQoL questions by themselves (Upton et al., 2008). In addition, it has been argued that children have limited capacities to adopt a long-term perspective of events and consequences and a restricted attention span (Ravens-Sieberer, 2006). In contrary, research has shown that even young children who are provided with the opportunity to self-report HRQoL with age-appropriate instruments demonstrate sufficient introspective abilities, are capable to use rating scales and common response terms, can understand and interpret underlying concepts, and are able to produce reliable and valid answers about their HRQoL (Cremeens, Eiser, & Blades, 2006; Riley, 2004). It is important to take into account the developmental level of the children, as constructs of self-esteem and quality of life can have different meanings to children of different ages (Cremeens, Eiser, & Blades, 2006; Levi, Drotar, & Erlbaum, 1998).

There is evidence that the level of child-parent agreement for Child HRQoL measures is highly variable, in particular for aspects that reflect non-observable behavior and internalizing symptoms (Eiser & Morse, 2001; Eiser & Varni, 2013; Ravens-Sieberer, 2006; Upton et al., 2008). Studies that examined child-parent concordance have typically done so in the process of developing and establishing a new HRQoL measure. For example, the KIDSCREEN study group has reported satisfactory to good agreement between youth and proxy reports for all KIDSCREEN versions with highest agreement for physical aspects and school environment and less agreement regarding the children’s social connections and psychological aspects (Ravens-Sieberer, 2006). The PedsQL^{TM} demonstrated low child-parent agreement in a study with 149 healthy children between the aged of 5 and 8 years, whereby agreement varied with the children’s age and the HRQoL aspects. Higher agreement was reported for younger age on physical health, compared to higher agreement for older age on psychosocial aspects of health (Cremeens, Eiser, Blades, et al., 2006). Both studies assessed concordance with intraclass-correlation coefficients. Child-parent agreement on standardized child HRQoL instruments may vary with the respondents’ characteristics and the HRQoL domain under investigation. The resulting degree of measurement error associated with these discrepancies illustrates that the exploration of the usefulness of a patient-centered approach is essential in evaluating treatment efficacy. Children and parents may both provide different information on multiple aspects of child HRQoL. Parent-proxy ratings of child HRQoL should be considered when children are unwilling or unable to self-report, for example because they are too young, ill or fatigued (Varni, Limbers, & Burwinkle, 2007). Ideally, they are used in addition as a secondary outcome measure not in substitution of child self-reports, as children know best about their internal states. To minimize measurement error, they should assess the same constructs with parallel items (Cremeens, Eiser, & Blades, 2006).

Interrater reliability for child HRQoL measures may vary depending on characteristics inherent to both raters (e.g., the raters’ age, gender, health status and life satisfaction, family situation, sociodemographic variables) as well as on the HRQoL domain being assessed.

Child Characteristics. Research indicates that the child’s mental health status has an impact on child-parent agreement (Dey, Landolt, & Mohler-Kuo, 2013; Eiser & Varni, 2013; Upton et al., 2008). The impact of the child's age and gender on child-parent agreement and the direction of effects is less clear due to inconsistent study results (Britto et al., 2004; Klassen, Miller, Fine, & development, 2006; Loonen, Derkx, Koopman, & Heymans, 2002; Robitail et al., 2006b; Ronen, Streiner, Rosenbaum, & Epilepsia, 2003; Waters, Stewart-Brown, Fitzpatrick, & development, 2003; White-Koning et al., 2007).

The Child's Mental Health Status. The children's health status has been found to influence the child-parent agreement. Parents of healthy children tend to report higher child HRQoL scores than the children themselves, whereas parents of children with clinical conditions, both physical and psychiatric, tend to underestimate child HRQoL (Dey, Landolt, Mohler-Kuo, et al., 2013; Eiser & Varni, 2013; Upton et al., 2008). Interrater reliability is better when children suffer from physical illnesses than from mental illnesses compared to healthy populations (Kiss et al., 2009). The better observability of physical symptoms may explain this conclusion (Eiser & Morse, 2001; Eiser & Varni, 2013; Upton et al., 2008). Inconsistent results have been reported regarding the impact of symptom severity on the concordance between raters. It has been assumed that parents of children with severe health conditions communicate more with their children about disease-related symptoms and are more attentive regarding these symptoms (Eiser & Varni, 2013). Concordantly, interrater reliability was higher when children suffered from an active physical disease compared to an inactive disease (remission or absence of disease activity) (Ringold, Wallace, & Rivara, 2009). However, only modest child-parent agreement has been found when children had chronic pain conditions (Vetter, Bridgewater, & McGwin, 2012).

The Child's Age. Some studies have found higher concordance between parents and younger children (Al-Uzri et al., 2013; Cremeens, Eiser, Blades, et al., 2006; Rajmil, López, López-Aguilà, & Alonso, 2013) whereas others have reported the opposite (Annett, Bender, DuHamel, & Lapidus, 2003; Ronen et al., 2003). The inconsistency in results may be explained by the fact that interrater reliability may vary for certain HRQoL domains in different developmental stages. For example, in a longitudinal study of newly-diagnosed pediatric cancer patients (*n* = 222 child-parent dyads), differences in HRQoL ratings were greatest in the oldest children (13-17 years) for emotional, social and school functioning and in the youngest age group (5-7 years) for physical functioning (Eiser & Varni, 2013). Eiser & Varni (2013) argue that interrater reliability is a complex interplay between the child's developmental level and the HRQoL domain that is being assessed by parents. On the one hand, parents spend more time with younger children which enhances their awareness of the child's functioning, and on the other hand, younger children may have more difficulties than their older peers disclosing their emotional needs to parents due to insufficient language skills. Older children can communicate their needs more easily. However, the parents' proxy reports may be less accurate children spend more time with peers and activities outside the home setting (Eiser & Varni, 2013).

The Child's Gender. Inconsistent findings exist also regarding the impact of the child's gender on HRQoL agreement. Whereas the literature review by Eiser & Morse (2001) on HRQoL did not find an association between gender and mother-child agreement, some studies showed higher agreement between parents and boys on HRQoL ratings (Jokovic, Locker, Stephens, & Guyatt, 2003), others reported higher agreement for girls (Robitail et al., 2006b). Slightly better agreement between boys and their parents may be attributed to the boy's tendency to exhibit and report more externalizing symptoms (Penney & Skilling, 2012). Externalizing behavior is more observable for parents and therefore leads to higher child-parent agreement compared to internalizing behavior that is more frequently reported by girls (Eiser & Morse, 2001; Penney & Skilling, 2012).

Parental Characteristics. Multiple studies have examined the impact of family characteristics include sociodemographic factors (e.g., parental gender, socioeconomic status), aspects related to the quality of child-parent relationship and the quantity of interactions, as well as the parent's mental health and HRQoL perceptions on agreement between the children's self-reported HRQoL and proxy-ratings by parents. Research indicates that the parent's relationship to the child, as well as their own HRQoL perceptions and mental health are more predictive of child-parent agreement than the parent's sociodemographic characteristics.

The Parent's Relationship to The Child. The quality of child-parent relationship and the amount of shared time with the child partly determines the level of agreement between child-self reports and parent-proxy reports. A low quality child-parent relationship, characterized by low parental acceptance of the child, as well as a high frequency and intensity of parent-child conflicts, has been found to be significantly related to discrepancies in ratings on children's externalizing behavior (Kolko, Kazdin, & psychiatry, 1993). Similarly, parents who spend more time with their children seem to be better informed about the child's emotions and behavior. Studies found that mothers who spent more time with their child made more accurate assessments on their offspring's internalizing behavior than did the fathers who were less present in their child's daily life (Jensen, Xenakis, Davis, & Degroot, 1988; Treutler & Epkins, 2003). Informant discrepancies seem also be related to the family functioning in general. The level of agreement has been determined by the parental living situation (parents divorced vs. living together), and the intimacy between family members (De Los Reyes & Kazdin, 2005), suggesting that high family functioning increases concordance between informants. On the contrary, family dysfunction, characterized by frequent conflicts, family burden and distress, decreases interrater reliability, probably attributable to inadequate communication strategies employed by family members (Grills, & Ollendick, 2002).

The Parent's HRQoL. Empirical research revealed that parents' proxy-reports on child HRQoL are not only related to their own mental health status but also to their subjective HRQoL perception (Berman et al., 2016a; Cremeens, Eiser, Blades, et al., 2006; Eiser & Morse, 2001; Eiser & Varni, 2013). Significant correlations were found between parents' own HRQoL and their proxy-reports of child HRQoL of a sample of 149 healthy children aged between 5 and 8 years and 103 parents (Cremeens, Eiser, Blades, et al., 2006). Similar interaction effects of parental quality of life and child self-reported quality of life have been found in other studies (Eiser, Eiser, & Stride, 2005; Goldbeck &

Melches, 2005). Parents who reported higher own quality of life rated their children's well-being as higher, too (Berman et al., 2016a). It has been suggested that parents project their own feelings on to judgements about their child's functioning (Cremeens, Eiser, Blades, et al., 2006).

The Parent's Mental Health Status. Research indicates that the parent's mental health influences their subjective perceptions of their offspring's mental health and HRQoL. Parents with higher levels of emotional distress and depressive symptoms had more negative perceptions of their child's HRQoL than did parents who were less distressed (Janicke et al., 2007; Kobayashi, & Kamibeppu, 2011). The higher the symptom severity and the perceived symptom burden of parents, the more mental health symptoms were reported for their children (Moretti, Fine, Haley, & Marriage, 1985). The association between parental depressive symptoms and negative child HRQoL ratings appeared to be stronger for mothers than for fathers (Davis, Davies, Waters, & Priest, 2008). The presence of mental health symptoms in one parent can also influence the perspective on their child's emotional and behavioral symptoms. Both mothers with depressive symptoms and their healthy partners reported more psychological problems in the child than did couples without any mental disorder (Luoma, Koivisto, & Tamminen, 2004).

The Parent's Sociodemographic Characteristics (Gender, Socioeconomic Status). Most research on agreement between child self-report and parent-proxy report regarding the offspring's HRQoL relate to mothers, impeding the interpretation of gender effects. Studies taking both perspectives into account are rare, even in the context of mental health research (Alakortes et al., 2017). The majority of studies on HRQoL contradicts the assumption of relevant parental gender effects on interrater reliability and suggest that potential gender effects rather originate from differences between parents regarding the quality of child-parent relationship and quantity of child-parent interactions (Loonen et al., 2002; White-Koning et al., 2007). Nevertheless, although parents rate their children's quality of life similar in most domains, their focus may vary slightly so that they can contribute a unique perspective on specific aspects of their child's behavior. A meta-analysis containing 60 studies and 126 independent effect sizes investigated interparental agreement on the child's internalizing, externalizing and total problem behavior. Both parents exhibited moderate correspondence in rating of internalizing behavior problems and large correspondence regarding externalizing and total behavior problems in children (Duhig, Renk, Epstein, Phares, & Practice, 2000). As parents vary in their awareness, sensitivity and tolerance of children's health concerns, both fathers and mothers should be consulted for parent-proxy ratings of child HRQoL, if possible.

Similarly, previous studies did not identify salient associations between sociodemographic factors like country of birth, the parent's living status (living with or without a partner), employment, and educational level, and child-parent agreement on HRQoL (Berman et al., 2016a; Silva et al., 2015) or psychopathology ratings (De Los Reyes & Kazdin, 2005). It has been suggested that the extent and direction of rating discrepancies is better explained by familial factors (e.g., family relationships, caregiving burden) than by sociodemographic factors.

The HRQoL Domain. The HRQoL domain that is being assessed partly determines the informant's rating concordance. Parents make more accurate proxy-ratings when they assess objective aspect of their child's health status (e.g., physical functioning) and have more difficulties with the assessment of subjective aspects like their child's emotional state and social relationships (Ravens-Sieberer, 2006; White-Koning et al., 2007). Similarly, agreement have been found higher for externalizing mental health symptoms (e.g., hyperactivity, aggression) than for internalizing symptoms (e.g., depression, pain, fatigue), as externalizing behavior is more visible for external raters (Achenbach, McConaughy, & Howell, 1987; Eiser & Morse, 2001; Eiser & Varni, 2013; Rajmil et al., 2013; Upton et al., 2008; Varni et al., 1996). The discrepancies reported in emotion-focused HRQoL items appears to become more discordant in adolescence compared to younger age groups (Chang & Yeh, 2005). One explanation for this might be that adolescents spend more time in extrafamilial settings and prefer to communicate their emotional needs to peers rather than to discuss them with their parents (Eiser & Varni, 2013). Parents frequently lack insight into parts of their children's life that exist outside the home setting, leading to discrepancies in ratings. Research has identified lower interrater reliabilities for HRQoL domains for which raters rely on different sources of information (e.g., peer interactions) (Parsons, Barlow, Levy, Supran, & Kaplan, 1999; Sawyer, Antoniou, Toogood, & Rice, 1999). One exception seem to be HRQoL questions related to the school setting for which high child-parent agreement has been reported (Kiss et al., 2009; Robitail et al., 2006b). Although the school setting is not directly observable by parents, they can rely on information provided by teacher and evaluate the academic achievement.

2.4. HRQoL of Partners of Parents with Mental Illness

In the past, patients suffering from severe mental illness were commonly institutionalized. With advances in medicine, pharmacology, psychotherapy, and policies, more people with mental illness have moved into the community. The challenges of caregivers of relatives with mental illness have been studied since early 1950's when psychiatric hospitals began to discharge patients to the community (Chan, 2011). While some patients with mental illness are able to successfully live an independent live, probably with the support of ambulant services, others depend on the assistance by family members who help them to manage their activities of daily living. For example, about 25-50% of people with schizophrenia in western countries stay with their family after discharge from hospital and depend on their caring abilities (Chan, 2011). Even when patients with mental illness do not live at home, for example when they receive inpatient care, family members often provide ongoing care and support (Lively, Friedrich, & Rubenstein, 2004; Ratner, Zendjidjian, Mendyk, Timinsky, & Ritsner, 2018). The World Federation of Mental Health has recognized the global importance of caregivers and their ever-expanding role because the resources of health and social services are challenged (World Federation of Mental Health, 2010). It has also been recognized that the burden of caregivers for people with mental illness is a common challenge in both developed and developing countries (Chan, 2011).

Caring for mentally ill relatives can be a stressful experience that requires tireless effort, energy, time, and empathy, and it has a huge impact on caregivers' daily lives (Chan, 2011; World Federation of Mental Health, 2010). Numerous studies have shown that family caregivers of a person with mental illness suffer from significant distress, up to 83 percent of the relatives experience high levels physical, psychological, social, and financial burdens, and often receive inadequate assistance from mental health professionals (Chan, 2011; Lorenza Magliano et al., 2002; Settineri, Rizzo, Liotta, & Mento, 2014). Research indicates that the burden of caring for mentally ill individuals is higher than caring for individuals with disabilities like mental retardation (Rudnick, 2004). Another study indicated that healthy partners of parents with mental illness display worse HRQoL compared with healthy partners of cancer patients. Reduced HRQoL of healthy parents had in turn detrimental effects on their children's adjustment, which may further increase the burden of the healthy parent (Krattenmacher et al., 2014).

Most research that examined the burden and quality of life of caregivers of patients with mental illness focused on schizophrenia (Dyck, Short, & Vitaliano, 1999; Foldemo et al., 2005; Grandón et al., 2008a; Hanzawa et al., 2013; Hou, Ke, Su, Lung, & Huang, 2008; Lauber, Eichenberger, Luginbühl, Keller, & Rössler, 2003; Zendjidjian et al., 2012). Other studies investigated this topic in the context of affective disorders (Grover et al., 2014; Zendjidjian et al., 2012) and obsessive compulsive disorder (Torres, Hoff, Padovani, & Ramos-Cerqueira, 2012). Results consistently indicate that caregivers are less satisfied with their overall quality of life and that their care responsibility results in significant distress (Angermeyer, Kilian, Wilms, & Wittmund, 2006; Foldemo et al., 2005; Hsiao et al., 2020; Martens & Addington, 2001; Sales, 2003). Previous findings show that the caregiver burden is closely related to the concept of HRQoL. For example, among caregivers of patients with schizophrenia (Hsiao et al., 2020; Kate, Grover, Kulhara, & Nehra, 2013) and obsessive-compulsive disorder (Gururaj, Math, Reddy, & Chandrashekar, 2008) caregiver burden was directly related to poor quality of life outcomes. Those findings are in line with research on physical illness (Jeong, Jeong, Kim, & Kim, 2015; Morimoto, Schreiner, & Asano, 2003). For instance, a survey with more than 200 stroke caregivers reported that the significant effect of caregiver health status, income, duration of hospitalization and spouses caring for patients on caregivers' quality of life was mediated by caregiver burden (Jeong et al., 2015).

From a general perspective, relatives of people with mental illness show primarily diminished quality of life in psychology ical, social and physical domains (Angermeyer et al., 2006; Fleischmann & Klupp, 2004). For instance, a study that examined quality of life of more than 4300 spouses of outpatients with different mental disorders (schizophrenia, depression, anxiety) found that the spouses' quality of life was significantly lower compared with the general population in the quality of life domains mental health and social relationships (Angermeyer et al., 2006). However, the most impaired aspects of quality of life in family members of mentally ill people may vary with the patient's psychiatric diagnoses. For example, the most severe impairment of quality of life in caregivers of individuals with affective disorders concerned psychological distress as well as social and role disability due to emotional problems (Zendjidjian et al., 2012). Another study examined the emotional burden of 47 relatives of patients with obsessive-compulsive disorder. The authors concluded that a greater level of psychological morbidity and burden in caregivers was associated with the perception of interference in personal life, the perception of patient's dependency, embarrassment as well as feelings of insecurity resulting from not knowing whether they should set limits regarding the patient's safety-seeking behaviors (Torres et al., 2012). The findings suggest that policies and clinicians should address these specific needs through educational and support groups for caregivers (Dixon et al., 2004; Torres et al., 2012; Zendjidjian et al., 2012).

It has been criticized that past studies have primarily focused on the disadvantages of caregiving and have neglected the positive aspects of caregiving that promote resilience in family members and mediate or moderate the caregiver burden (Chan, 2011). Bauer et. al. (2012) conducted 60 semistructured interviews with caregivers of patients with mental illness. The transcripts contained negative and positive aspects of coping that were evaluated with a summarizing content analysis. Growth in character was the most rewarding aspect that compromised an increase in self-confidence, inner strength, maturity, and life experience (Bauer, Koepke, Sterzinger, & Spiessl, 2012). Rewarding aspects of caregiving can strengthen the caregivers' resilience, which has been defined as the ability to overcome adversity and to manage the daily caring burden, and to grow into a stronger, more flexible and healthier person (Van Breda, 2001; Zauszniewski et al., 2009).

Multiple risk and protective have been identified from previous research that predict caregiver resilience and quality of life. For example, caregivers' resilience can be compromised by risk factors like caregiver strain, perceived stigmatization, client dependency or family dysfunction, and can be enhanced by protective factors like optimism and hopefulness, resourcefulness (i.e., cognitive and behavioral skills necessary to keep functioning on an optimal level), a sense of coherence (i.e., the belief that the world is comprehensible, manageable and meaningful), and a positive relationship with the cared person (Bland & Darlington, 2002; Lauber et al., 2003; Zauszniewski et al., 2009). Some of the most relevant determinants of caregivers' quality of life were selected for further consideration in this dissertation. They include factors that are associated with characteristics of psychopathology in the cared person, caregivers' coping behavior, family functioning, mental health symptoms in the caregiver or in their children, social support, and psychosocial circumstances.

2.3.1. HRQoL Determinants of Partners of Parents with Mental Illness

2.3.1.1. Characteristics of Psychopathology

Research on schizophrenia found that the caregiver burden of adults caring for relatives with mental illness is predicted by the patients' clinical characteristics including symptom severity, illness duration, a higher frequency of relapses, suicidal ideation and behavioral disturbances (Grandón et al., 2008b; Hjärthag, Helldin, Karilampi, & Norlander, 2010; Hsiao et al., 2020; Maeng et al., 2016; Ohaeri, 2001; Settineri et al., 2014; Stanley, Balakrishnan, & Ilangovan, 2017). In addition, a study with 66 patients with schizophrenia found that the presence of caregiver burden was predicted by the patient's compliance with medication, psychosocial functioning, the participation in psychosocial rehabilitation program, the diagnostic subtypes and the mean daily hours spent with the patient (Koukia & Madianos, 2005). It has been suggested that psychosocial rehabilitation programs can improve the patients' communication skills, reduce the degree of dependency on their relatives and decrease the time spent at home. As a consequence, the subjective burden of caregivers can significantly be reduced (Koukia & Madianos, 2005). Caregivers' quality of life may be especially reduced at the time of the initial stages of the mental illness (Addington, Coldham, Jones, Ko, & Addington, 2003) and during acute episodes (Lauber et al., 2003).

Some psychopathologies appear to be more burdensome for caregivers than others, although the study results should be interpreted with caution as caregiver burden and quality of life were measured with different instruments and some of the sample sizes were rather small. For instance, a French study group compared the quality of life of 246 caregivers of individuals with schizophrenia and 232 caregivers of individuals with affective disorders (Zendjidjian et al., 2012). In line with another study (Möller–Leimkühler, 2006) caregivers of schizophrenic patients report lower quality of life than caregivers of patients with affective disorders (Zendjidjian et al., 2012). The emotional burden of family members of people with obsessive-compulsive disorder has been considered to resemble or is even higher than that of family members of affective (Magliano, Tosini, Guarneri, Marasco, & Catapano, 1996; Vikas, Avasthi, & Sharan, 2011) or schizophrenic disorders (Kalra, Nischal, Trivedi, Dalal, & Sinha, 2009).

There is evidence that the proximity of the caregiver to the patient has a greater impact on caregivers' quality of life than the symptom severity of the patient. Caregivers of patients with affective disorders or schizophrenia report lower quality of life when they share the same household (Yazici et al., 2016; Zendjidjian et al., 2012). However, even caregivers who do not share their household with the mentally ill relative can have a decreased mental health as indicated by a Korean study with 116 caregivers of individuals with schizophrenia (Hanzawa et al., 2013). The caregivers in this study were traumatized by the violent behavior of a family member with schizophrenia and they still experienced mental illness. The authors suggested that the persistent psychological burden is facilitated through stigmatization by association and the policy-based obligation of family members to care for individuals with mental illness (Hanzawa et al., 2013).

2.3.1.2. Coping Behavior of Partners

The appraisal of stressors and the coping behavior of adult family members affects their HRQoL perceptions. The importance of stress appraisal and coping has been illustrated by the results of

Möller-Leimkkühler (2006) which indicate that at least part of the predictors of relatives' stress levels are independent of the patients' psychopathology. The longitudinal study followed relatives of first hospitalized patients with schizophrenia or depression. At one-year follow-up most of the 69 caregivers still had a remarkable level of burden although the subjective quality of life improved in two third of the relatives compared to baseline. The most relevant predictors of relatives' stress outcome were the relatives' expressed emotion and neuroticism, their generalized negative stress response and life stressors that included either chronic everyday burden (e.g., financial problems, caring for small children) or stressful life events in the last six months (e.g., moving, birth of a child). They had either significant direct or indirect effects explaining up to 75% of the total variance of relative's stress levels. The authors concluded that interventions should focus more on improving the relatives' general stress response and coping abilities in order to lower the relatives' burden and improve their quality of life (Möller–Leimkühler, 2006). When relatives learn to improve their coping strategies, for example through psychoeducational interventions, the burden of the patients' mental illness can be reduced even after several years of chronic illness (Magliano et al., 2000).

Family members of people with mental illness can apply adaptive and maladaptive coping strategies to deal with stressful situations. Adaptive strategies decrease not only the immediate stress level but also decrease the likelihood of its occurrence in the future. They promote health and quality of life (Griva & Anagnostopoulos, 2010; Grover & Pradyumna, 2015) and include active problem-oriented strategies, the search for social support, self-growth and the focus on one's strengths and positive attributes, positive reframing, humor (Draine & Solomon, 1995; van der Sanden, Pryor, Stutterheim, Kok, & Bos, 2016). Some maladaptive coping strategies may reduce the negative impact of a stressor temporally, however in the long-term they can even reinforce distress (Krägeloh, 2011; Moore et al., 2011; van der Sanden, Pryor, Stutterheim, Kok, & Bos, 2016). Maladaptive coping strategies result in poor mental health outcomes and HRQoL (Draine & Solomon, 1995; Lee et al., 2014; Mohr et al., 2014; Vollrath et al., 2003). They include avoidance, denial, self-blame, substance use, self-distraction, behavioral disengagement and venting negative emotions (van der Sanden, Pryor, Stutterheim, Kok, & Bos, 2016).

Previous research that have used cognitive models of stress and coping (Folkman & Lazarus, 1984) to describe and examine various factors that mediate the relationship between stressful situations and the psychological outcomes in relatives of mentally ill patients. Loughland et al. (2009) have summarized those mediating factors in the context of aggression and trauma experiences among relatives who care for people with psychosis. They include the relatives' subjective appraisal of the patients' symptoms and behaviors (Barrowclough, Tarrier, & Johnston, 1996; Boye et al., 2001), the threat appraisal related to the patients' aggressive behavior (Brewin, Andrews, & Valentine, 2000; Holbrook, Hoyt, Stein, & Sieber, 2001; Ozer, Best, Lipsey, & Weiss, 2003), the relative's attributions about the causes of such behaviors (Barrowclough et al., 1996), and the relatives' selection of coping strategies (Magliano et al., 2000). Relatives of people with mental illness are more likely to use maladaptive coping strategies when they feel unable to control and change the stressful situation, and when the threat appraisal is high (Brewin et al., 2000; Ehlers & Clark, 2000; Holbrook et al., 2001; Lazarus & Folkman, 1984; Quinn, Barrowclough, & Tarrier, 2003). The results of an online survey with 107 family members of patients with early psychosis indicate that the family members' cognitive appraisal about the mental illness, its consequences and their perceived caregiving role significantly predict the family members' quality of life. While negative cognitive appraisals were strongly associated with lower quality of life in family members, positive cognitive appraisals predicted enhanced quality of life and adaptive family functioning (Gupta & Bowie, 2018). The self-efficacy beliefs of relatives are higher when they possess about enough knowledge and skills to deal with the patients' mental illness. They are then more likely to perceive the stressful situation as controllable and changeable, and are more likely to use adaptive coping strategies (Chan, Yip, Tso, Cheng, & Tam, 2009; Lim & Ahn, 2003). Many family members of mentally ill patients report that they have insufficient knowledge and skills to cope with their family members' mental illness as indicated by a randomized controlled trial that evaluated the effectiveness of a psychoeducation program for Chinese clients with schizophrenia and their family members. The psychoeducation intervention by Chan and colleagues significant improved self-efficacy beliefs and satisfaction of caregivers and reduced the caregiver burden (Chan et al., 2009). Another study indicated among relatives of patients with schizophrenia those with more knowledge about the mental illness exhibited more adaptive coping (Lim & Ahn, 2003). When relatives' blame themselves for the patients' psychopathology, they are more likely to use negative or emotion focused coping strategies (Barrowclough et al., 1996; Magliano et al., 2000). For instance, a study involving relatives of schizophrenia patients found that when relatives believed that illness events were caused by factors internal to themselves, they experienced more distress. The level of distress had no impact on the relatives' beliefs about the patients' role in stressful situations (Barrowclough et al., 1996). Relatives with higher face concern (i.e., concern that one's social image and social worth is diminished due to one's performance in social contexts), which may result from stigmatization and social exclusion, were more likely to internalize feelings of shame, to self-blame oneself for the patients' illness, to feel powerless and to report poor mental health in an Chinese sample with family relatives of people with intellectual disability (Yang, 2015). Stigmatization of family members of patients with mental illness increases the probability to use the maladaptive strategy avoidance coping (Hanzawa, Bae, Tanaka, Bae, et al., 2010; Hanzawa, Bae, Tanaka, Tanaka, et al., 2010).

Research has consistently indicated that in particular with regard to mental illness, the caregiver burden and quality of life is primarily linked to the personality characteristics and the mood of the caregiver himself (Da Silva et al., 2014; Hou et al., 2008; Lautenschlager, Kurz, Loi, & Cramer, 2013; Möller-Leimkühler & Mädger, 2011; Möller–Leimkühler, 2006; Settineri et al., 2014). A German 5-year longitudinal study followed 64 caregivers of patients with depression and schizophrenia who were hospitalized for the first time (Möller-Leimkühler & Mädger, 2011). Caregivers of patients with schizophrenia had higher levels of neuroticism and reported a higher subjective burden compared to caregivers of depressed patients. Out of the five personality factors (neuroticism, extraversion, openness, agreeableness, conscientiousness), neuroticism was the most relevant predictor of caregiver burden and self-reported mental health symptoms which showed direct and indirect effects. Relatives who are high in neuroticism are more likely to assess and interpret stressors more negative, and to react to distress with psychological and somatic complaints, suggesting that family interventions should target the perceptual distortion in order to enhance the caregivers' quality of life (Möller-Leimkühler & Mädger, 2011). The results are in accordance with a previous longitudinal study of Möller-Leimkühler (2006) involving relatives of hospitalized patients with schizophrenia or depression. A higher stress level in relatives was predicted by high levels of neuroticism along with a generalized negative stress response and low levels of expressed emotion (Möller–Leimkühler, 2006).

In summary, relatives of people affected by mental illness experience many stressful events. The way how they appraise and cope with distress affects their quality of life and mental health (Möller-Leimkühler & Mädger, 2011; Vollrath et al., 2003). Whether relatives of patients with mental illness experience a high or low burden is determined by the relatives' subjective (threat) appraisal of the patients' symptoms and behaviors, the relative's attributions about the causes of such behaviors, and the relatives' selection of coping strategies which can either be adaptive or maladaptive (Loughland et al., 2009). (Hanzawa, Bae, Tanaka, Bae, et al., 2010; Hanzawa, Bae, Tanaka, Tanaka, et al., 2010). The quality of life and caregiver burden is influenced to a great extent by the relatives' personality characteristics and mood (da Silva et al., 2014; Hou et al., 2008; Lautenschlager, Kurz, Loi, & Cramer, 2013; Möller-Leimkühler & Mädger, 2011; Möller–Leimkühler, 2006; Settineri et al., 2014).

2.3.1.3. Family Functioning

While high functional families (e.g., high levels of emotional disclosure, open and respectful family communication, well-defined roles, good affect regulation) can improve the HRQoL of relatives of mentally ill patients by providing them with social support and enhancing their efficacy-beliefs (Bandura et al., 2011; Lewandowski et al., 2010; Rüsch et al., 2019), dysfunctional families (e.g., many conflicts, low emotional expression, impaired communication) can cause distress and diminish the relatives' HRQoL (Wang et al., 2016; Zeng et al., 2020). Relatives of people with mental illness are more likely to live in dysfunctional families than people from the general population (Freed et al., 2015; Koutra et al., 2014; Letourneau et al., 2013; Vogt et al., 2017; Wang et al., 2016). A study found that families of patients with obsessive compulsive disorder experienced burden mainly because of the disruption of family routine, family interactions and family leisure activities (Vikas et al., 2011). In another study family members of patients with psychosis reported extreme family difficulties including disengagement, rigidity and chaos compared to healthy control families (Gupta & Bowie, 2018).

A recent cross-sectional study explored the association between family functioning and quality of life in 121 family caregivers of patients with schizophrenia. Family functioning was more related to the caregivers' mental health and less to their physical health. The regression analyses showed that better quality of life mental health in family caregivers of patients with schizophrenia was associated with better family adaptability (i.e., a family's ability to adapt and change stressors) and affective responsiveness (i.e., the ability to respond appropriately to the expressed emotions by family members) (Meng et al., 2021). The adaptability of families is positively correlated with adaptive coping behavior (Tramonti, Barsanti, Bongioanni, Bogliolo, & Rossi, 2014) and positive stress appraisals in caregivers (Gupta, 2017) as well as with emotional support from family members (Jiang et al., 2015). In consequence, caregivers can better deal with challenges associated with psychopathology in their relatives. Caregivers of people with mental illness who are able and encouraged to express emotions, even negative ones, report better quality of life (Kwon & Kim, 2019; Meng et al., 2021). Emotional responsiveness can increase emotional support from family members and enhance the caregivers quality of life (Marroquín, Czamanski-Cohen, Weihs, & Stanton, 2016).

Psychopathology in parents can adversely affect intimate partnerships, as evidenced by a high number separations and divorces (Idstad et al., 2015; Mowbray et al., 2000). People who are single, separated or divorced report significantly lower HRQoL than people who have intimate partnerships (McCaffrey et al., 2016). Proper sexual functioning is one of the most relevant determinants of quality of life and marital satisfaction (Zemishlany & Weizman, 2008). However, sexual dysfunction is common among people with mental illness including patients schizophrenia, anxiety disorders, depressive disorders, eating disorders and personality disorders (Basson & Gilks, 2018; Kantipudi, Suresh, Ayyadurai, & Ramanathan, 2020; Martín, Acuña, Labrador, Blanco, & Casas, 2018; Zemishlany & Weizman, 2008). Sexual dysfunction may be related to psychopathology, to pharmacotherapy or interpersonal conflicts (Zemishlany & Weizman, 2008).

The way how family members interaction with each other and the functional level of families is influenced by the characteristics of psychopathology such as symptom type and severity, relapse frequency, and suicidal tendencies (Grandón et al., 2008b), psychosocial circumstances (e.g., financial situation, employment status (Mowbray et al., 2000; Nicholson et al., 2002; Plass-Christl et al., 2017b) and characteristics of the family (e.g., family communication) (Rüsch et al., 2019).

2.3.1.4. Mental Health Symptoms in Caregivers

The prevalence mental health symptoms in relatives of patients with mental illness is high. It has been estimated that caregivers of patients with mental illness are more than two times more likely to suffer from depressive disorders than the general population (Heru, Ryan, & Madrid, 2005; Magaña, Ramirez Garcia, Hernández, & Cortez, 2007). Because the burden of relatives partly depends on the patients' clinical characteristics, prevalence rates of mental health symptoms in family members may vary with the patients' psychiatric diagnosis and the associated burden. Studies on psychosis indicate that about one third of the relatives experience depressive or anxiety-related symptoms that can be attributed to their caregiving role and poorer quality of life than population norms (MacCarthy et al., 1989; Poon, Harvey, Mackinnon, & Joubert, 2017). A systematic review on caregivers of patients with borderline personality disorder reported that caregivers self-reported objective and subjective burden were half a standard deviation above the mean compared to people who care for inpatients with other serious mental illnesses. This was reflected by higher rates of mental health symptoms including depressive and anxiety-related symptoms (Bailey & Grenyer, 2013).

The elevated rates of mental health problem in relatives of patients with mental illness can be explained by multiple factors. Whereas some of the risk factors are shared by most relatives, some other factors are more related to specific disorders. General stressors relate to stigmatization, social isolation and loneliness, emotional frustration, guilt, family conflicts, financial problems and occupational dysfunction, disruption of routine and social activities, as well as inadequate assistance from mental health professionals (Chan, 2011; Vadher et al., 2020). From a disorder-specific perspective, family members of patients with psychotic disorders like schizophrenia often face daily distress due to the patients' unpredictable and bizarre behaviors (Chan, 2011). A high rate of patient relapses and readmissions may further distress the relatives (Chan & Yu, 2004; Martens & Addington, 2001). Caregivers of patients with alcohol use disorder are likely to experience repeated quarrels, verbal and physical abuse, seclusion of caregivers from other family members and society (Vadher et al., 2020).

Several studies have investigated factors that predict mental health symptoms in relatives of patients with mental illness. However, many of them have focused on the prediction of caregiver burden which is only indirectly associated with mental health symptoms and quality of life (Vadher et al., 2020). A study examined the severity of caregiver burden and its association with depression, anxiety and quality of life among 50 caregivers of patients with alcohol use disorder and schizophrenia. Relatives who experienced a high caregiver burden were significantly more likely to display depressive and anxiety related symptoms as well as poor quality of life. While the caregiver burden of relatives of patients with schizophrenia was predicted by anxiety in caregivers, environmental health, socioeconomic status and patients' occupation, the caregiver burden associated with alcohol use disorder was predicted by depression in caregivers and environmental health (Vadher et al., 2020). Derajew and colleagues (2017) have summarized the predictors of mental health symptoms in caregivers that have been identified in other studies. The summary indicates that depression among caregivers of patients with mental illness is positively associated with younger age and lower school education of the caregiver (Magaña et al., 2007; Singh & De Sousa, 2011), being assaulted by the patient (Fernando, Hanwella, Rajapakse, De Silva, & Rodrigo, 2013), a high occurrence of stigmatization by association (Magaña et al., 2007), an increased number of hours spent with providing care, older age of the caregiver and duration of care giving (El-Tantawy, Raya, & Zaki, 2010), being non-religious and not believing in spirituality (Murray-Swank et al., 2006) and poor social support (Biegel, Katz-Saltzman, Meeks, Brown, & Tracy, 2010; Derajew, Tolessa, Feyissa, Addisu, & Soboka, 2017; Hsiao et al., 2020).

2.3.1.5. Mental Health Symptoms in Children

Children of parents with mental illness have an increased risk of diminished mental health (McLaughlin et al., 2012; Plass-Christl et al., 2017a; Weber et al., 2017a; Wiegand-Grefe et al., 2011; Wiegand-Grefe et al., 2009) which decreases the quality of life of parents (Foldemo et al., 2005; Plass-Christl et al., 2017b; Vasilopoulou & Nisbet, 2016) and enhance their risk of psychopathology (Cooper et al., 2006). Parents of children with mental illness are vulnerable to self-blame (Moses, 2010), they commonly report feelings of helplessness, anger, anxiety and worries about the future (Ambikile & Outwater, 2012). Furthermore, parents whose spouses and children suffer from mental health symptoms have to help their family members to organize and adhere to clinical appointments which can be stressful for caregivers, especially when they lack resources (e.g., financial, transportation), professional and social support (World Health Organization, 2003; Scharer et al., 2009). Family treatments may be particular useful in such family constellation (Lauritzen, Reedtz, Rognmo, Nilsen, & Walstad, 2018; Scharer et al., 2009; Siegenthaler, Munder, & Egger, 2012; Tabak et al., 2016).

2.3.1.6. Social Support

Caregiver burden, depressive symptoms and decreased quality of life of family members of mentally ill patients has been linked to inadequate levels of social support (Chien, Chan, & Morrissey, 2007; Perlick et al., 2007; Wiegand-Grefe et al., 2012). A cross-sectional study among 181 Chinese caregivers of family members with serious mental illness found that social support had a significant correlation with caregivers’ quality of life. Caregivers in this study received low social support, in particular with regard to objective support and utilization of social support. They also displayed little support seeking behaviors (Leng, Xu, Nicholas, Nicholas, & Wang, 2019). Another study found that insufficient social support was the most significant predictor of depressive symptoms in caregivers, followed by caregiver burden (Saunders, 2003). Grandón et. al. (2008) conducted a hierarchical regression analysis to examine the burden of 101 Chilean primary caregivers of schizophrenia outpatients. Among other factors, decreased social interests, less affective support, and low independence-performance in social situations predicted caregiver burden (Grandón et al., 2008a).

Research indicates that social support is an important protective factor of caregiver quality of life and burden in diverse cultures (Chan, 2011). People who remain active in various social roles (e.g., spouse, professional, parent) and who spend more time with recreational and social activities report better quality of life (Ay-Woan et al., 2006; Eklund, 2001; Kim & Rew, 1994; Weeder, 1986). Social support promotes mental and physical health as well as quality of life by increasing health-promoting behaviors, by promoting positive role function and behaviors, psychosocial adjustment, adaptive coping behaviors, self-actualization, and by providing a person with a sense of meaning in life (Ay-Woan et al., 2006; Callaghan & Morrissey, 1993; Wang et al., 2003; Y. Zeng, Zhou, & Lin, 2017).

There are many explanations for insufficient social support of family members of mentally ill patients. Family members of people with mental illness may lack the time for personal entertainment, recreational activities and social engagement (Wong, Lam, Chan, & Chan, 2012). They may also have reduced time for full- or part-time employment and thus lack social contacts in the occupational setting (Leng et al., 2019). Stigmatization can further facilitate social isolation and feelings of loneliness (Chien et al., 2007). Research has consistently demonstrated that much of the caregiver burden and distress experienced by relative of patients with mental illness is related to the stigma associated with mental illness (Chan, 2011; Zauszniewski et al., 2009). Zauszniewski and colleagues (2009) concluded based on a literature review that stigmatization leads to 'social isolation of families, financial difficulties, occupational restrictions, frustration, anxiety, low self-esteem, helplessness, reduction in leisure activities, negative effects on social relationships, experiences of discrimination and refusal, and worry about the future' (Muhlbauer, 2002; Rose, Mallinson, & Gerson, 2006; Tsang, Tam, Chan, & Chang, 2003; Zauszniewski et al., 2009). According to Chan (2011), stigma is a global phenomenon which poses a threat to the self-esteem, interpersonal relationships and employment of people with schizophrenia and their families. It results in prejudice and discrimination and discourages families affected by parental psychopathology to seek help (Chan, 2011; Hanzawa et al., 2013). To reduce social stigma to mental illness and enhance the availability of a supportive social network, community-based family interventions and support group should be developed, and culture-specific health education on mental illness, its consequences and treatments should be provided (Chan, 2011).

All in all, the research findings emphasize the importance to enhance social support in caregivers of mentally ill patients. If caregivers do not have adequate social and professional support, their quality of life may be diminished due to an increased burden. Moreover, they may be less able to take on caring responsibilities, thus leading to relapse or readmission in patients (Chan, 2011). Community-based interventions ensuring a social support network such as peer support groups have proven to effectively reduce the burden of family members of mentally ill patients (Ohaeri, 2001; Saunders, 2003). Leng et al. (2018) suggest that caregivers should be encouraged to seek help from other family members, friends or professionals in providing care, especially when family members provide long-time care and are unemployed. Caregivers' quality of life may be enhanced when mental health education campaigns assist in increasing the social network (Leng et al., 2019). Furthermore, it has been proposed that health policymakers should recognize the demanding role of caregivers and provide relatives of patients with mental illness relevant resources including financial assistance (Zeng et al., 2017) and asstist them in maintaining and increasing their supportive social network (Leng et al., 2019).

2.3.1.7. Psychosocial Circumstances

Adverse psychosocial circumstances such as financial problems, stressful life events (e.g., custody loss) are common among families affected by parental mental illness and can reduce HRQoL of family members (Kaplan et al., 2019; Luciano et al., 2014; Madianos et al., 2004; Mowbray et al., 2000; Nicholson et al., 2002). In addition, demographic characteristics such as the age and gender of the other healthy parent affect individual perceptions of HRQoL (Hsiao et al., 2020; B. Janssen & Szende, 2014; Opoku-Boateng et al., 2017; Souza et al., 2017; Yazici et al., 2016; Zendjidjian et al., 2012)..

An empirical study with about 60 caregivers of patients with obsessive compulsive disorder or depression reported that families of patients with obsessive compulsive disorder experienced burden due to the financial burden resulting from the patients' unemployment, treatment costs and the family members' limited capacity to work due to caring responsibilities (Vikas et al., 2011). Financial strains are common in families with parental psychopathology (Luciano et al., 2014). The employment status of family members of inpatients with schizophrenia is significantly associated with the physical, psychological, social domains and environmental aspects of HRQoL (Hsiao et al., 2020; Yazici et al., 2016; Yu et al., 2017). Unemployed or on-leave family members of mentally ill patients have more financial strains and a smaller social network, which lowers their HRQoL (Hsiao et al., 2020; Leng et al., 2019). Hsiao et al. (2020) concluded that with higher socioeconomic status families are more likely to have sufficient social and financial resources to meet the needs of caregiving demands. Probably for the same reason, higher education of family caregivers is associated with better psychological HRQoL (Hsiao et al., 2020; Opoku-Boateng et al., 2017). People with higher levels of education generally have better job prospects and higher salaries (OECD, 2012).

The caregivers' demographic characteristics such as their age and gender are related to quality of life. Studies indicate that the older primary family caregivers are the higher the caregiver burden and the poorer their HRQoL (Hsiao et al., 2020; Souza et al., 2017; Yazici et al., 2016). The gender distribution of caregivers for ill family members is unequal with a higher proportion of female caregivers partly because caregiving is seen as a female responsibilities and moral obligation in many cultures (Hsiao et al., 2020; Ntsayagae, Poggenpoel, & Myburgh, 2019). Female family member of people with mental illness tend to report a greater caregiver burden and worse quality of life than their male counterparts (Fleischmann & Klupp, 2004; Opoku-Boateng et al., 2017; Vadher et al., 2020; Zendjidjian et al., 2012). Those age and sex- related differences reflect a trend that has also been observed in the general population (Janssen & Szende, 2014). Representative international population-based surveys indicate that overall HRQoL decreases with increasing age, and that men of all age groups report higher overall HRQoL than women (Janssen et al., 2019). It has been proposed that age-differences in HRQoL reflect a higher occurrence of physical and mental impairments with older age. There are several explanations for HRQoL differences between men and women. First, it has been suggested that women experience more often sociodemographic disadvantages (e.g., lover average income than males, higher proportion of singles) that can lower their quality of life (Cherepanov et al., 2010; Michelson et al., 2000; Wijnhoven et al., 2003). Second, female caregivers may differ in their stress appraisal and coping behavior and lack more social support than male caregivers (Vadher et al., 2020). Furthermore, men and women differ on their experiences of the type of burden as indicated by a study with patients with bipolar affective disorders (Bauer et al., 2011). Bauer and colleagues (2011) reported that while female caregivers reported more problems regarding the quality of the relationship with the patient, male caregivers felt more restrictions on their own autonomy.

2.5. The Link Between Family Members' HRQoL

The mental illness of one family member can not only compromise the HRQoL of that person but also the HRQoL of the family members (Comer et al., 2010; Dittrich et. al., 2018; Goetz et al., 2017; Hagen et al., 2019; Kang et al., 2020; Vadher et al., 2020; Zauszniewski et al., 2009). Negative experiences of caregivers may affect their ability to provide adequate care for the mentally ill patient. There is evidence that the HRQoL of a person is affected by the life satisfaction of closed others (Bergelt et al., 2008; Caqueo-Urízar et al., 2017; Hjärthag et al., 2008; Parabiaghi et al., 2007; Perlick et al., 2006; Rhee & Rosenheck, 2019; Sun et al., 2019). This may apply in particular to family caregivers who have a close relationship with the mentally ill patient (Jungbauer & Angermeyer, 2002; Rudnick, 2004).

Only one South American study has directly investigated the relationship between the quality of life of patients with mental illness and the quality of life of their family members (Caqueo-Urízar et al., 2017). This study examined the relationship between caregivers' quality of life and the quality of life of 253 stabilized adult outpatients with schizophrenia. Half of the adult caregivers were mothers and the other half was unspecified. In the multivariate analyses, the caregivers' quality of life was not significantly associated with the patients' quality of life, except for the quality of life dimension family relationships. However, the structural equation model detected a significant association between the caregivers' quality of life and the patients' quality of life that was mediated by psychotic symptom severity. The authors concluded that the improvement of the caregivers' quality of life can directly affect the psychotic symptoms of the patient and indirectly the patients' quality of life (Caqueo-Urízar et al., 2017).

A few other studies have demonstrated that low patient quality of life increases the burden or relatives (Hjärthag et al., 2008; Parabiaghi et al., 2007; Perlick et al., 2006; Rhee & Rosenheck, 2019). Although those studies did not directly assess the caregivers' quality of life, the results are still informative as a high caregiver burden is directly related to poor caregiver quality of life (Gururaj et al., 2008; Hsiao et al., 2020; Kate et al., 2013). A study from the United States followed 446 principal family caregivers of patients with schizophrenia and investigated the association of changes in patients' quality of life and mental health symptoms with changes in caregiver burden. Half of the caregivers were the parents of the patients, about 16% were spouses, 5% were adult children of the patients and the rest were other relatives. Weak and insignificant associations were found between clinical changes in patient symptoms and quality of life with changes in family caregiver burden. The authors suggest that small clinical improvements in clinical symptoms in chronically ill patients are insufficient to affect the long established burden of family caregivers (Rhee & Rosenheck, 2019). In another study family 623 caregivers of patients with schizophrenia were interviewed. Although the quality of life of the patients contributed to the family's experience of burden, the contribution appeared relatively modest compared with the contribution of the patients' symptoms. The caregivers reported greater patient helpfulness and lower impairment in activities of daily living when patients had higher quality of life ratings (Perlick et al., 2006). A longitudinal cohort-study of 51 caregivers of patents with schizophrenia showed that half of the caregivers experienced significant emotional distress at baseline assessment. The severity of family burden was significantly associated with poor patients' quality of life along with more severe psychopathology and lower patients' functioning (Parabiaghi et al., 2007).

Other studies have examined the link between family members' quality of life in families affected by physical illness (Goldbeck & Melches, 2005) or in healthy families (Ngai & Ngu, 2013; Sun et al., 2019). Goldbeck and Melches (2005) conducted a study with 69 children suffering from congenital heart disease and their caregivers. They showed that the parental quality of life was significantly correlated both with the children's self- and parent-rated quality of life. The parental quality of life moderated the parental proxy-reports. Two Asian studies found that the quality of life of healthy couples was significantly weakly to moderately correlated during the perintal period (Ngai & Ngu, 2013) and during the transition to parenthood (Sun et al., 2019).

3. Research Objectives and Hypotheses

3.1. HRQoL of Parents with Mental Illness (Research Objective 1)

The purpose of the first research objective was to examine HRQoL of parents with mental illness by first comparing the sample's global and specific HRQoL with results from the general population, and second by examining the association between their HRQoL and various risk and protective factors. The analyses included a selection of HRQoL determinants that are commonly observed in clinical populations (e.g., mental and physical health). The consideration of parent related HRQoL determinants (e.g., child psychopathology) extended previous research. It was assumed that each HRQoL determinant had a significant association with the outcome.

3.2. HRQoL of COPMI (Research Objective 2)

The first aim was the comparison of children's HRQoL with HRQoL of children from the general population. Child HRQoL estimates were based on the child's self-reports, the proxy reports of the mentally ill parent and the partners. Second, the association between overall child HRQoL and various child and family related risk and protective factors (e.g., parental mental symptom burden) was explored. The third aim was the systematic investigation of the magnitude and direction of child-parent agreement regarding overall child HRQoL as well as its association with selected child and family related factors. It was hypothesized that children and their parents self- and proxy-report significantly lower child HRQoL compared to the general population. It was assumed that the child- and family-related risk and protective factors were significantly associated with child HRQoL. Moreover, it was hypothesized that children's self- and parents' proxy-reports showed fair congruence regarding child HRQoL and that the selected factors (e.g., family functioning) were significantly associated with child-parent (dis)agreement.

3.3. HRQoL of Partners of Parents with Mental Illness (Research Objective 3)

This objective aimed to compare the HRQoL of adults who support their mentally ill partners care for their children with reference data. Second, the association between various risk and protective factors and the partners' HRQoL was examined. It was hypothesized that partners report significantly lower overall HRQoL compared to adults from the general population and that each HRQoL determinant was significantly associated with the outcome.

3.4. The Link Between Family Members' HRQoL (Research Objective 4)

The fourth research objective aimed to compare family members' self-reported HRQoL with each other. It was hypothesized that family members' HRQoL reports were significantly correlated. No assumptions were made about the relative strength of the associations between family members' HRQoL. However, it was hypothesized that parents self-reported HRQoL had higher correlations with child HRQoL when the latter was proxy-reported by the parents themselves as opposed to the child self-reports.

4. Methods

4.1. Study Design

All analyses of this dissertation were conducted using the baseline data of the randomized controlled multicenter CHIMPS (children of mentally ill parents) project ‘Implementation and evaluation of a family-based intervention program for children and adolescents of parents with mental illness”. The study was financed by the German Federal Ministry of Education and Research and participants’ data were obtained between 2014 and 2018. The aim of the CHIMPS project was the improvement of the children’s mental health and quality of life in the short- and long-term by implementing and evaluating a manualized family intervention. Participants provided questionnaire- and interview-related data at the baseline assessment as well as 6, 12, and 18 months after baseline. To evaluate treatment effectiveness, families were randomized after the baseline assessment either to the family intervention CHIMPS or to a control condition (TAU). The eight theme-specific sessions of the CHIMPS intervention were conducted with either the whole family, the children or the parents. Themes covered include psychoeducation, disease coping, social support, family relations and communication. A detailed description of the intervention (Wiegand-Grefe, Halverscheid, et al., 2011) and the study design (Wiegand-Grefe et al., 2021) has been published.

Parents with mental illness and their families were recruited from in- and outpatient departments of psychiatric units in seven participating study centers located in Germany and Switzerland. The study centers compromised both university and regular community hospitals to reflect the actual health care situation and to facilitate the representativeness of the sample. The study centers were involved in patient recruitment, diagnostics and the implementation of the CHIMPS intervention. Participants were recruited at the end of the patients’ treatment period by their availability and willingness to serve as participants in the project. Study participation required at least one psychiatric diagnosis assessed by clinicians in charge according to the formal International Classification of Diseases (ICD-10). Comorbid psychiatric diagnoses were allowed. Participants with acute symptomatology requiring (further) inpatient treatment were excluded. Parents with mental illness had at least one child aged between 1-19 years with whom they had regular personal contact (at least every two weeks). To compensate for the time and effort associated with the completion of the questionnaires and interviews, each family received a staggered financial compensation.

The Ethics Committee of the regional Medical Association (Hamburg, Germany) has approved the CHIMPS project under the number PV4744. All participants were informed about the project objectives and procedures, voluntariness and confidentiality. Written informed consent was obtained from all adult participants. Children under the legal age of 18 years provided written assets and the permission of their parents.

4.2. Participants

The overall project sample compromised of *n* = 216 families with *n* = 216 parents with mental illness, *n* = 338 children and adolescents aged 1-19 years, and *n* = 145 partners. Partners had either a current or past intimate relationship with the patient and were significantly involved in child-rearing.

The individual sample sizes and characteristics varied slightly for each research objective due more than 30% questionnaire-related missing data or because the questionnaires had differing age requirements. For example, the CBCL 4-18 required children to be 4-18 years old while the KIDSCREEN-27 required children to be 8-18 years old. Due to differing research questions, some research objectives (2,4) required the analyses of all participant groups, while others (1,3) excluded specific participant groups. Furthermore, the number of children that were included for analyses slightly varied among research objectives due to differing rating perspectives. For instance, the first research objective evaluated child-related data only when it was proxy-reports by parents with mental illness while the third research objective considered only proxy-reports of partners. An overview of the sample sizes is presented in *Table 1.*

Table 1. Sample sizes (n) by research objectives

	Overall CHIMPS project sample	Research Objective			
		1	2	3	4
Families (*n*)	216	208	134	141	208
Parents with mental illness (*n*)	216	208	134	-	208
Children (*n*)	338	197	198	140	198
Partners (*n*)	145	-	94	141	141

Note. The sample characteristics of the overall CHIMPS project are presented in *Table 2 – Table 4*. A detailed description of the sample characteristics relating to each research objective can be found in the appendix (*Table 25-36, Appendix A*). The research objectives examined the HRQoL of parents with mental illness (1), children (2), partners (3) and explored the link between family members HRQoL (4).

For the first research objective (HRQoL of parents with mental illness) data were analyzed of *n* = 208 families containing *n* = 208 parents with mental illness and *n* = 197 children and adolescents aged 8-18 years for whom the parents with mental illness provided proxy-reports. Eight families were excluded from the overall project sample due to more than 30% questionnaire-related missing values.

The final sample for the second research objective (HRQoL of COPMI) included *n* = 134 families containing *n* = 134 parents with mental illness, *n* = 198 children and adolescents aged 8-18 years and *n* = 94 partners. Regarding the children and adolescents, child self-reports (*n* = 136) and proxy-reports of parents with mental illness (*n* = 189) and partners (*n* = 141) were considered. One child self-report could not be used due to more than 30% missing data.

The third research objective (HRQoL of partners) analyzed the data of *n* = 141 families containing *n* = 141 partners and *n* = 140 children and adolescents aged 8-18 years for whom the partners provided proxy-reports. The self-reports of four partners were excluded because they had more than 30% questionnaire-related missing data.

Lastly, the fourth research objective examined the link between the HRQoL of family members with data provided by *n* = 208 parents with mental illness (self-reports), *n* = 198 children aged 8-18 years (self- and proxy-reports by both parents), and *n* = 141 partners (self-reports). Due to more than 30% missing data, self-reports of eight parents with mental illness, one child and four partners could not be considered.

Parents of the overall CHIMPS project sample were on average 40 years old. While approximately two third of the parental patient sample was female, the opposite gender-distribution was found for the partner sample. Half of the parents with mental illness were married. A higher proportion of spouses was found in the partner sample. Parents had on average two children. Most of them received 10-13 years of school education. The child sample had a mean age of nine years. Males and females were equally represented. The majority of the children shared the household with the mentally ill parent and partners, and most of them had (step)siblings. Parents with mental illness were primarily diagnosed according to the ICD-10 with mood (affective) disorders (F30-F39, for example major depressive disorder), followed by disorders of adult personality and behavior (F60-F69, for example paranoid personality disorder), neurotic, stress-related and somatoform disorders (F40-F48, for example phobias, obsessive-compulsive disorder). Fewer patients had the primary psychiatric diagnoses schizophrenia, schizotypal, and delusional disorders (F20–F29, for example delusional disorder) and only a small proportion of the parental patient sample were diagnosed with mental and behavioral disorders due to psychoactive substance use (F10–F19, for example alcohol dependence) and behavioral and emotional disorders with onset usually occurring in childhood and adolescence (F90–F98, for example attention deficit hyperactivity disorder). Almost half of the parents with mental illness had psychiatric comorbidities. Whereas the subjective psychiatric symptom burden of parents with mental illness was on average clinically remarkable (BSI raw score ≥ 0.62), the partner sample reported on average no clinically remarkable symptoms. Parents with mental illness coped with distress by primarily employing trivialization and wishful thinking, active problem-oriented coping, and depressive coping. The partners of parents with mental illness used primarily active problem-oriented coping to deal with stressful situations. Both parental samples used adaptive coping strategies more often than maladaptive ones. Half of the parents with mental illness reported physical impairments, but only one third of the partners had physical complaints. Parents with mental illness self-reported on average *M* = 36.69 (*SD* = 15.29) on family functioning assessed with the FB-A while partners self-reported a mean of *M* = 30.86 (*SD* = 15.12) and children self-reported on average *M* = 30.86 (*SD* = 13.38). The parents self-reported social support assessed with the OSSS-3 ranged from *M* = 8.20 (*SD* = 2.41; parents with mental illness) to *M* = 9.58 (*SD* = 2.58; partners). The parental proxy-assessments of child support were slightly higher than that of the children who self-reported an average social support of *M* = 10.11 (*SD* = 2.27). The partner sample was more satisfied with current

HRQoL than the moderately satisfied parents with mental illness. The majority of parents with mental illness expressed problems with anxiety/depression, followed by pain/discomfort and usual activities. One fourth of them reported any problems with self-care and mobility. Half of the partner sample reported any problems with pain/ discomfort, followed by anxiety- and depression-related problems, problems with usual activities and mobility. Only four partners reported self-care problems. Regarding children's mental health symptoms assessed with the CBCL 4-18 only children and adolescents between 4-18 years could be considered due to the CBCL 4-18 age requirement. Mental health symptoms in children were assessed from all perspectives with children reporting more problems (*M* = 67.03, *SD* = 21.12) than both of their parents. Parents with mental illness proxy-reported more mental health symptoms in children (*M* = 37.90, *SD* = 25.72) than did their partners (*M* = 26.47, *SD* = 21.70). Regarding child HRQoL the KIDSCREEN-27 required children to be 8-18 years. Child HRQoL was assessed from all rating perspectives with similar assessments of overall quality of life that indicate moderate life satisfaction.

Table 2. Characteristics of parents with mental illness

Characteristics	*n* (%)	*M* (*SD*)	Possible Score Range
Parents with mental illness			
Sociodemographic data[1,a]			
Age (in years)		40.04 (7.13)	
Female	157 (75.1%)		
Married	112 (54.4%)		
Number of children		1.91 (0.93)	
School education			
11-13 years education	65 (32.2%)		
10 years education	90 (44.8%)		
9 years education	42 (20.9%)		
No secondary education	4 (2.0%)		
Mental health			
Psychiatric diagnosis (ICD-10)[2, b]			
F10 – F19	3 (1.4%)		
F20 – F29	11 (5.1%)		
F30 - F39	124 (57.7%)		
F40 - F48	26 (12.1%)		
F60 - F69	50 (23.3%)		
F90 – F98	1 (0.5%)		
Comorbidity (ICD-10)[2,b]	89 (41.2%)		
Psychopathology (BSI, GSI)[1,c]		1.34 (0.69)	0-4
Parental Coping (FQCI)[1,d]			
Depressed processing style		3.16 (0.74)	1-5
Active problem-oriented coping		3.22 (0.76)	1-5
Distraction and self-growth		2.81 (0.57)	1-5
Religiosity and quest for meaning		2.59 (0.69)	1-5
Trivialization and wishful thinking		3.61 (1.02)	1-5
Adaptive coping		3.01 (0.60)	1-5
Maladaptive coping		2.79 (0.57)	1-5
Physical impairments[1,a]	102 (50.2%)		
Family functioning (FB-A, total score)[1,e]		36.69 (15.29)	0-120
Social support (OSSS-3, total score)[1,f]		8.20 (2.41)	3-15
HRQoL (EQ-5D-3L)[1]			
Mobility (any problems)	48 (23.0%)		1-2
Self-care (any problems)	56 (26.8%)		1-2
Usual activities (any problems)	136 (65.1%)		1-2
Pain/ discomfort (any problems)	144 (68.9%)		1-2
Anxiety/depression (any problems)	184 (88.0%)		1-2
VAS		54.32 (19.68)	0-100
Index		0.56 (0.22)	-0.21-1

Note. n = 216 parents with mental illness. Questionnaire-related scores were based on raw data; for details see text (Methods). [1] based on parent self- and proxy reports. [2] based on proxy-ratings by clinicians. [a] ad-hoc items [b] International Classification of Diseases (ICD-10) codes: mental and behavioral disorders due to psychoactive substance use (F10–F19), schizophrenia, schizotypal, and delusional disorders (F20–F29), mood (affective) disorders (F30–F39), neurotic, stress-related and somatoform disorders (F40–F48), disorders of adult personality and behavior (F60–F69), behavioral and emotional disorders with onset usually occurring in childhood and adolescence (F90–F98), [c] Brief-Symptom Inventory, [d] Freiburg Questionnaire of Coping with Illness, [e] General Family Questionnaire, [f] Oslo Social Support Scale.

Table 3. Characteristics of children and adolescents aged 1-19 years

Characteristics	*n* (%)	*M* (*SD*)	Possible Score Range
Children aged 8-18 years			
Sociodemographic data[a]			
Age (in years)[2]		9.63 (4.37)	
Female[2]	169 (51.8%)		
Shared household with mentally ill parent[2]	283 (89.6%)		
Shared household with partner[2]	208 (93.3%)		
(Step) siblings[1]	129 (62.0%)		
HRQoL (child self-report) [1]			
KIDSCREEN-10 index		34.62 (4.43)	10-50
KIDSCREEN-27, physical well-being		14.94 (3.73)	5-25
KIDSCREEN-27, mental health		21.24 (2.48)	7-35
KIDSCREEN-27, autonomy and parents		27.43 (5.36)	7-35
KIDSCREEN-27, social support and peers		15.81 (3.61)	4-20
KIDSCREEN-27, school environment		14.75 (3.50)	4-20
HRQoL (mentally ill parent proxy-report)[2]			
KIDSCREEN-10 index		37.84 (6.71)	10-50
KIDSCREEN-27, physical well-being		15.04 (3.66)	5-25
KIDSCREEN-27, mental health		26.45 (5.91)	7-35
KIDSCREEN-27, autonomy and parents		27.49 (5.32)	7-35
KIDSCREEN-27, social support and peers		15.81 (3.62)	4-20
KIDSCREEN-27, school environment		14.72 (3.48)	4-20
HRQoL (partner proxy-report)[3]			
KIDSCREEN-10 index		37.74 (5.55)	10-50
KIDSCREEN-27, physical well-being		15.68 (3.40)	5-25
KIDSCREEN-27, mental health		26.37 (5.05)	7-35
KIDSCREEN-27, autonomy and parents		27.83 (4.12)	7-35
KIDSCREEN-27, social support and peers		14.10 (3.49)	4-20
KIDSCREEN-27, school environment		14.68 (3.31)	4-20
Mental health (YSR/ CBCL 4-18, total problems)[b]			
Child self-report[1]		67.03 (21.12)	0-112
Mentally ill parent proxy-report [2]		37.90 (25.72)	0-113
Partner proxy-report[3]		26.47 (21.70)	0-113
Family functioning (FB-A)[c]			
Child self-report[1]		30.86 (15.12)	0-120
Mentally ill parent proxy-report [2]		36.69 (15.29)	0-120
Partner proxy-report[3]		30.48 (13.38)	0-120
Social support (OSSS-3)[2, d]			
Child self-report[1]		10.11 (2.27)	3-15
Mentally ill parent proxy-report [2]		8.78 (1.64)	3-15
Partner proxy-report[3]		9.58 (2.58)	3-15

Note. *n* = 338 children and adolescents aged 1-19 years. Questionnaire-related scores were based on raw data; for details, see text (Measures). [1] based on child self-reports. [2] based on the mentally ill parent proxy-reports. [3] based on the partner proxy-report. Measures: [a] ad-hoc items, [b] Youth Self-Report/ Child-Behavior Checklist 4-18, [c] General Family Questionnaire, [d] Oslo Social Support Scale.

Table 4. Characteristics of partners

Characteristics	*n* (%)	*M* (*SD*)	Possible Score Range
Partners[1]			
Sociodemographic data [a]			
Age (in years)		40.26 (7.10)	
Female	51 (36.4%)		
Married	102 (72.9%)		
Number of children		1.98 (0.92)	
School education			
11-13 years education	53 (39.3%)		
10 years education	51 (37.8%)		
9 years education	30 (22.2%)		
No secondary education	1 (0.7%)		
Mental health			
Psychopathology (BSI, GSI) [b]		0.51 (0.52)	0-4
Parental Coping (FQCI) [c]			
Depressed processing style		2.19 (0.73)	1-5
Active problem-oriented coping		3.29 (0.75)	1-5
Distraction and self-growth		2.86 (0.75)	1-5
Religiosity and quest for meaning		2.43 (0.81)	1-5
Trivialization and wishful thinking		1.94 (0.86)	1-5
Adaptive Coping		3.07 (0.66)	
Maladaptive Coping		2.18 (0.58)	
Physical impairments [a]	49 (35.5%)		
Family functioning (FB-A, total score) [d]		30.48 (13.38)	0-120
Social support (OSSS-3, total score) [e]		9.58 (2.58)	3-15
HRQoL (EQ-5D-3L)			
Mobility (any problems)	22 (15.7%)		1-2
Self-care (any problems)	4 (2.9%)		1-2
Usual activities (any problems)	29 (20.7%)		1-2
Pain/ discomfort (any problems)	70 (50.0%)		1-2
Anxiety/depression (any problems)	46 (32.9%)		1-2
VAS		74.43 (19.20)	0-100
Index		0.81 (0.16)	-0.21-1

Note. *n* = 145 partners. [1] based on self- and proxy reports of partners. Questionnaire-related scores were based on raw data; for details, see text (Methods). [a] ad-hoc items, [b] Brief-Symptom Inventory, [c] Freiburg Questionnaire of Coping with Illness, [d] General Family Questionnaire, [e] Oslo Social Support Scale.

4.3. Measures

4.3.1. HRQoL of Parents

The EQ-5D-3L (Rabin et. al., 2011) is a generic standardized measure of current health and HRQoL developed by the EuroQol Group. The paper-pencil version is cognitively undemanding and takes a few minutes to complete. The self-report questionnaire provides a simple descriptive profile, a single summary index value (EQ-5D-3L Index) and a visual analogue scale (EQ-5D-3L VAS) for clinical and economic appraisal. The EQ-5D-3L index is calculated based on country-specific value sets (utility weights) that indicate the preferences from the general population's perspective. In general, the best possible health is represented by an index with a maximum utility weight of 1, whereas death is indicated by an index of 0. However, the worst possible health state for the German EQ-5D-3L index can even take a value of -0.21 which indicates health states worse than death (Greiner, Claes, Busschbach, & von der Schulenburg, 2005). VAS values range from 0 (worst imaginable health state) to 100 (best imaginable health state). The VAS is a quantitative assessment of health outcome reflecting the patient's own judgement at that day. Besides overall HRQoL the EQ-5D-3L measures domain-specific aspects by means of five subscales, each consisting of one question: mobility (e.g., 'I have no problems in walking around'), self-care (e.g., 'I have some problems washing or dressing myself'), usual activity (e.g., 'I have no problems performing my usual activities (e.g., work, study, housework, family or leisure activities)'), pain/ discomfort (e.g., 'I have moderate pain or discomfort'), anxiety/ depression (e.g., 'I am extremely anxious or depressed'). Items are generally rated within three severity levels: no problems, some problems, extreme problems (labelled 1-3). In this dissertation the severity levels were summarized, which results in a dichotomous outcome indicating the proportion of respondents scoring any problem (the sum of the proportion of level-2 and level-3 problems). This dichotomization makes it possible to compare the sample's HRQoL with HRQoL of the general population (Sonntag et al., 2013). The EQ-5D-3L has proven to be valid, reliable and responsive in numerous conditions and populations (Rabin et al., 2011; Sonntag et al., 2013; Yfantopoulos & Chantzaras, 2017).

4.3.2. HRQoL of Children

The children's HRQoL was measured with the child self- and parent-proxy version of the KIDSCREEN-27, which correspond in scale structure, item content and answer choices (Ravens-Sieberer, 2006). The standardized KIDSCREEN-27 is applicable to children and adolescents aged 8-18 years. The paper-pencil version takes 10-15 minutes to complete. The 27-item version of the KIDSCREEN covers five domain-specific aspects of HRQoL: physical well-being (e.g., 'Have you felt fit and well'), mental health (e.g., 'Have you had fun? '), autonomy and parents (e.g., 'Have you felt that your parent(s) treat you fairly?'), social support and peers (e.g., 'Have you spent time with your friends?') and school environment (e.g., 'Have you been happy at school?'). Items are rated on a five-point response scale (0 = not at all to 4 = extremely or 0 = never to 4 = always). In contrast to most other HRQoL instruments, items on the KIDSCREEN-27 cover both negative and positive aspects of life in the past week. The KIDSCREEN-10 Index has 10 items and is derived from the 27-item version. Whereas the KIDSCREEN-27 focuses on domain-specific HRQoL, the KIDSCREEN-10 assesses overall HRQoL summarized into a single index score. Raw scores of the KIDSCREEN-10 range from 10 to 50 and for the KIDSCREEN-27 from 27 to 135. Higher values indicating better HRQoL. T-scores were based on European reference data with a mean of *M* = 50 and a standard deviation of *SD* = 10 (Ravens-Sieberer, 2006). T-scores smaller than 40 indicate low HRQoL, medium HRQoL is defined by T-scores between 40–60 and T-scores larger than 60 indicate high satisfaction with HRQoL. The KIDSCREEN-27 and KIDSCREEN-10 have good discriminatory power, high internal consistency (Cronbach's α = 0.80 to 0.84) and good test-retest reliability (Intra Class Correlation (ICC) = 0.61 to 0.70). The majority of studies with large sample sizes (minimum of 600 participants) have reported good to excellent child-parent agreement in most dimensions for healthy (Berman et al., 2016a; Ravens-Sieberer, 2006), mentally and physically ill children (Dey, Landolt, & Mohler-Kuo, 2013). In this study, the KIDSCREEN-27 demonstrated acceptable to good internal consistencies for the subscales of the child self-report (Cronbach's α = 0.65 to 0.84) the parent version (Cronbach's α = 0.73 to 0.91) Similarly, the KIDSCREEN-10 demonstrated good internal consistencies for both versions (Cronbach's α = 0.80 to 0.83). For details on internal consistency, see *Table 24* in the *Appendix*.

4.3.3. Parents' Mental Health

Brief Symptom Inventory (BSI) is a 53-item self-report questionnaire used to assess psychopathology in adults (Derogatis & Spencer, 1993). The paper-pencil version requires 10 minutes to complete. The global severity index (GSI) measures participants' current or past level of symptomatology, the number and intensity of reported symptoms of psychopathology that relate to the past seven days. GSI scores can range from 0 to 4 with higher scores indicating greater distress resulting from psychopathology. The GSI covers nine primary symptom dimension: somatization (e.g., 'Pains in heart or chest"), obsessive-compulsive (e.g., 'Having to check and double check what to do"), interpersonal sensitivity (e.g., 'Feeling shy or uneasy with the opposite sex"), depression (e.g., 'Feeling hopeless about the future"), anxiety (e.g., 'nervousness or shakiness inside"), hostility (e.g., 'Temper outbursts that you cannot control"), phobic anxiety (e.g., 'Feel afraid to go out of your house alone"), paranoid ideation (e.g., 'Feeling that you are watched or talked about by others"), and psychoticism (e.g., 'The idea that someone else can control your thoughts"). Questions on psychological distress are answered on five-point response scale ranging from 0 to 4 (0 = not at all/never, 4 = extremely/always). The authors reported good psychometric properties (Derogatis & Spencer, 1993). The BSI has high intercorrelations with established clinical rating scales, high convergent, discriminant and construct validity, and correlates highly with comparable dimensions of the original SCL-90-R version (Derogatis & Spencer, 1993). In this study, the internal consistency of the BSI GSI ranged from Cronbach's α = .96 to .97 depending on the research objective (see *Table 24* in the *Appendix*).

4.3.4. Children's Mental Health

Psychopathology in children was assessed with the Child Behavior Checklist 4-18 (CBCL-4-18) from the parents' perspectives and with the Youth Self Report (YSR) which is a self-report version for children and adolescents (Achenbach, 1991; Achenbach, Plück, & Kinnen, 2000; Döpfner, 1998; Döpfner, Plück, & Kinnen, 1998). Both standardized questionnaires are widely administered to identify maladaptive mental health symptoms in children aged 4-18 years that were observed during the past six months. The child-version has 112 items and the parent-version has 113 items that take approximately 15 to 20 minutes to administer. Raters assess the children's mental health symptoms on a three-point response scale from 0 ('not at all') to 2 ('often'). The CBCL 4-18 and the YSR provide a total problem score and two broadband scores referring to externalizing and internalizing symptoms based on eight syndrome scales: withdrawn (e.g., 'Would rather be alone than with others'), somatic complaints (e.g., 'Vomiting, throwing up'), anxious/depressed (e.g., 'nervous, high-strung, or tense'), social problems (e.g., 'Acts too young for his/her age'), thought problems (e.g., 'Feels others are out to get him/her'), attention problems (e.g., 'Can't concentrate, can't pay attention for Long'), delinquent behavior (e.g., 'Disobedient at school'), and aggressive behavior (e.g., 'Argues a lot'). Raw and T-scores were calculated according to the manual (Bird et al., 1987; Döpfner, Plück, Bölte, et al., 1998). Total raw scores range from 0 to 112 (child-version) or 0 to 113 (parent-version) with higher scores indicating greater psychopathology in children. The CBCL4-18 and the YSR are psychometrically sound instruments with established validity and reliability (Biederman et al., 1993; Bird et al., 1987; Döpfner, Plück, & Kinnen, 2014; Van Meter et al., 2014). Depending on the research objective, the internal consistency of the CBCL-4-18 total problem score varied between Cronbach's α = .94 and .95. The total score of the YSR had an internal consistency of .92 (see *Table 24* in the *Appendix*).

4.3.5. Parental Coping

Parental coping was assessed with the German Freiburg Questionnaire of Coping with Illness (FQCI; Muthny, 1989). The self-report version has 23 items used for scale formation and it requires approximately 5 minutes to complete. Respondents rate their predominant coping behavior on a four-point response scale ranging from 1 ('not at all') to 5 ('very much'). The five subscales include a depressed processing style (e.g., 'Pitying oneself'), active problem-oriented coping (e.g., 'Seeking information about illness and treatment'), distraction and self-growth (e.g., 'Giving oneself more treats'), religiosity and quest for meaning (e.g., 'Accepting illness as fate'), as well as trivialization and wishful thinking (e.g., 'Denying what happened'). The subscales can be summarized to differentiate between adaptive (active problem-oriented coping, distraction and self-growth) and maladaptive coping strategies (depressed processing style, religiosity and quest for meaning, trivialization and wishful thinking). The authors reported for the subscales internal consistencies between Cronbach’s α = .68 to .77 (Muthny, 1989). Similar internal consistencies had been established in this sample with Cronbach’s α being lowest for ‘Religiosity and Quest for Meaning” (Cronbach’s α = .49) and highest for ‘Trivialization and Wishful Thinking” (Cronbach’s α = .72). The Cronbach’s alpha of adaptive coping ranged from α = .76 to α = .79 and the Cronbach’s alpha of maladaptive coping ranged from α = .67 to α = .76 (see *Table 24* in the *Appendix*).

4.3.6. Family Functioning

The General Family Questionnaire (FB-A) measured participants’ family functioning (Cierpka & Frevert, 1994). The standardized self-report questionnaire has 40 items and takes approximately 45 minutes to complete. It generates a total score reflecting overall family functioning by summing up the seven subscales: task fulfillment (e.g., ‘We need to much time to deal with difficult situations’), role behavior (e.g., ‘The family duties are equally distributed’), communication (e.g., ‘We take time to listen to each other’), emotionality (e.g., ‘We share our true feelings with each other’), affectivity of relations (e.g., ‘We feel closely related’), control (e.g., When I ask why we have certain rules, I don’t get a satisfying response”), values and norms (e.g., ‘We have the same perspectives on what is right and wrong’). Respondents indicate their agreement with the statements on a four-point response scale from 0 (‘completely true’) to 3 (‘not true at all’). The total score ranged from 0 to 120 with higher scores reflecting greater family dysfunction. The authors reported an internal consistency of α > 0.60 for most subscales (Cierpka & Frevert, 1994). Here, the total score had an excellent internal consistency ranging from Cronbach’s α = .91 to .94 depending on the research objective (see *Table 24* in the *Appendix*).

4.3.7. Social Support

The Oslo Social Support Scale (OSSS-3) measured the participants’ perceived social support from friends, society and professionals (Dalgard et al., 2006). Parents were asked to self-report their availability of social support and to proxy-report the same for their children. The standardized questionnaire has three items asking for the number of close confidants, the sense of concern from other people as well as the relationship with neighbors and the accessibility of practical help. The scale of the first item has been adapted for study purposes from a 4 to a 5-point response scale (1 = none, 2 = 1–2, 3 = 3–4, 4 = 5–6 and 5 = more than 6). The summary of those three items results in a total score ranging from 3 to 15 with higher scores indicating greater social support. The OSSQ-3 has proven to be a valid and reliable questionnaire in a representative sample with 2524 German participants (Kocalevent et al., 2018). The internal consistency of the modified version used in this study ranged from Cronbach’s alpha α = 0.31 to α = .69 depending on the research objective (see *Table 24* in the *Appendix*).

4.3.8. Ad-hoc Items

In addition to the standardized questionnaires, individual items were formulated to measure the raters' self-reported sociodemographic characteristics (e.g., age, gender, marital status, education, living situation). Participants' physical health status was assessed with the item 'Are you currently suffering from physical illness?' with the answer choices 'yes/no'.

4.4. Data Analyses

A detailed description of data analyses conducted within the frame of each research objective is displayed in the following sections. Although the analyses differed for each research objective, they have some common aspects. Questionnaire-related scores were reported as raw values in all regression analyses. All continuous predictors were (grand) mean-centered. Participants with more than 30% missing values per measurement instrument were excluded (Rubin, 1976) and the remaining questionnaire-related missing values were imputed according to the expectation–maximization (EM) algorithm (Dempster, Laird, & Rubin, 1977). Data were graphically and statistically checked before data analyses to examine whether the data fulfilled the requirements for the applied statistical procedures. Statistical significance was set at $\alpha \leq .05$ two-sided. Data were analyzed with the statistics software IBM SPSS 25 (IBM, Armonk, NY, USA).

4.4.1. HRQoL of Parents with Mental Illness (Research Objective 1)

First, the observed proportion of respondents scoring any problem was compared to the reference population (Janssen et al., 2019) to examine whether the sample significantly deviated from the general population regarding domain-specific HRQoL. The binary probability of the subscales differentiated between no problems and any problems irrespective of their severity level. Global aspects of HRQoL (VAS, EQ-5D-3L Index) were compared through mean values. The association of various exposure variables (physical health, psychopathology, coping behavior, family functioning, social support, child psychopathology, sociodemographic information) with parents' self-reported global HRQoL was analyzed with multiple linear regression analyses with backward elimination. For domain-specific HRQoL, binary logistic regression analyses were conducted. Model 1 included all HRQoL determinants irrespective of their statistical significance. Predictors were then removed according to their impact on HRQoL starting with the predictor with the least impact. Model 2 contained therefore only the most contributing independent variables with significance $p < .100$. Parents were able to make more than one proxy-report (e.g., about the children's mental health) if they participated in this study with more than one child. To consider this cluster structure, proxy-reports for multiple children of the same family were summarized to reflect an average proxy-report of that family. Coefficients, standard errors and statistical significance of fixed and random effects were calculated and overall model fit was reported. Questionnaire-related scores were self- or proxy-reported by parents.

4.4.2. HRQoL of COPMI (Research Objective 2)

In the first step, it was analyzed weather the global and domain-specific HRQoL of children in this study sample differentiated significantly from the reference population (Ravens-Sieberer, 2006). The analyses considered the children's and both parents' perspectives on child HRQoL. In the second step, the impact of multiple child- (i.e., child psychopathology, social support, age and gender) and family-related predictors (i.e., parental psychopathology, family functioning, parental coping) on proxy-rated HRQoL of children was analyzed. Again, children's and both parents' perspectives were considered. Coefficients and standard errors of fixed and random effects were reported along with the corresponding significance values. Overall model fit was reported. Because children within families resembled each other more than children from different families (ICC $\geq .10$), linear mixed models were used to analyze the former two research questions.

To estimate child–parent agreement regarding global and specific, ICC estimates were calculated with a two-way mixed effects model along with confidence intervals and significance. The single measure setting has been used, resulting in an ICC that is an index for the reliability of the ratings for one, typical, single rater (Shumway-Cook, Brauer, & Woollacott, 2000). Both the consistency and absolute agreement definition were applied for ICC estimates. The consistency definition assumes that systematic differences between raters are irrelevant (Koo & Li, 2016; Shumway-Cook et al., 2000), whereas the absolute agreement considers relevant systematic differences among levels of ratings for the calculation of the ICC estimate (Nichols, 1998). Cicchetti's guidelines were used for interpretation with ICC < 0.4 indicating poor, 0.40–0.59 fair, 0.60–0.74 good, and 0.75–1.00 excellent reliability (Cicchetti & Sparrow, 1981). The analyzation of variables predicting total disagreement of HRQoL between children and parents with mental illness was performed with multiple linear regression. In contrast to the former research questions, ICC values were smaller than .10 suggesting that the family structure did not justify the use of linear mixed models. Total disagreement was calculated by subtracting the children's KIDSCREEN-10 index from the parents' KIDSCREEN-10 index. The exposure and outcome variables were assessed by parents with a mental illness.

4.4.3. HRQoL of Partners (Research Objective 3)

The first analysis of the third research objective aimed at comparing the global and domain-specific HRQoL of partners in this sample with reference data (Janssen et al., 2019) and to identify significant differences between the two groups. For global self-reported HRQoL measures (EQ-5D-3L VAS, EQ-5D-3L index) mean values were compared. Domain-specific differences in HRQoL were examined by comparing the binary probability of the subscales with the data drawn from the general population. Binary probability means the observed proportion of respondents reporting no problem vs. any problems with each subdomain irrespective of the severity level. In the next step, relevant risk and protective factors of HRQoL were identified. The association of self-reported global HRQoL of partners with multiple child- and family-related factors (physical health, psychopathology, coping behavior, family functioning, social support, child psychopathology, sociodemographic information) was analyzed with multiple linear regression analyses with backward elimination. The association with domain-specific aspect of HRQoL was examined with binary logistic regression analyses as the outcome had to levels (no problem vs. any problem). The backward elimination yielded two statistical models. Model 1 included all HRQoL determinants irrespective of their statistical significance. In Model 2, the independent variables were removed according to their statistical impact on the outcome variable starting with the predictor with the least impact. Hence, the final model contained only the most relevant factors associated with HRQoL of partner with a significance level of $p < .100$. Partners were able to make more than one proxy-report (e.g., about the children's mental health) if they participated in this study with more than one child. To consider probable family clusters, proxy-reports for multiple children of the same family were summarized to reflect an average proxy-report of that family. The analyses yielded coefficients, standard errors and statistical significance of fixed and random effects along with statistics of the overall model fit. All independent and dependent scores were either self- or proxy-reported by partners.

4.4.4. The Link Between Family Members' HRQoL (Research Objective 4)

To examine the link between family members' self-reported HRQoL, paired Pearson correlations were calculated to indicate the degree of convergence between family members' HRQoL. Bonferroni corrections were performed to adjust significance levels for multiple tests.

5. Results

5.1. HRQoL of Parents with Mental Illness

5.1.1. Average HRQoL of Parents with Mental Illness in Comparison to the General Population

Table 5 shows the self-reported global and specific HRQoL ratings of n = 208 parents with mental illness in comparison to the German reference population after age standardization (Janssen et al., 2019). Proportions of respondents scoring any problem with mobility, self-care, usual activities, pain/discomfort, and anxiety/depression are displayed along with the average self-reported global HRQoL expressed with the EQ-5D-3L VAS and the EQ-5D-3L Index. Parents with mental illness consistently self-reported lower global and specific HRQoL compared to the general population (most $p < .001$). The deviation in HRQoL from the reference population was most pronounced in the HRQoL domains anxiety and depression followed by usual activities, pain/discomfort, and self-care. The sample deviated less but significantly from the general population in terms of satisfaction with their mobility.

Table 5. Self-reported HRQoL scores after age standardization, mean EQ VAS, EQ Index and proportions (%) of respondents scoring any problem

EQ-5D-3L	German Population Norms	Sample	*p*
Mobility	17.2%	23.1% [17.5, 29.4]	.032*
Self-care	3.1%	26.4% [20.6, 33.0]	< .001***
Usual activities	10.5%	64.9% [58.0, 71.4]	< .001***
Pain/ discomfort	27.8%	68.8% [62.0, 75.0]	< .001***
Anxiety/depression	4.5%	88.0% [82.8, 92.1]	< .001***
VAS	*M* = 77.2	*M* = 54.22 [51.45, 56.98]	< .001***
Index	*M* = 0.90	*M* = 0.56 [0.53, 0.59]	< .001***

Note. n = 208. Square brackets indicate the 95% confidence interval; for details see text (Methods). *$p < .05$; **$p < .01$; ***$p < .001$

5.1.2. Risk and Protective Factors Associated with HRQoL of Parents with Mental Illness

The impact of multiple risk and protective factors on global and specific HRQoL of parents with mental illness is presented in *Table 6* and *Table 7 - Table 8* respectively. The determinants that appeared to be most related to parental global HRQoL were the patients' subjective physical health and psychopathology along with adaptive coping behavior. The higher parents with mental illness perceived their physical and mental health, and the more they used adaptive coping strategies like active problem-oriented coping, distraction and self-growth, the higher their satisfaction was regarding overall HRQoL. The significant determinants of HRQoL physical health, psychopathology and adaptive coping behavior explained 40% of the variance in the EQ5D index and 35% of the variance in the EQ5D VAS. The other risk and protective factors identified from previous research (maladaptive coping, family functioning, social support, child psychopathology, age and gender) did not contribute to the model. Approximately 60% of the variance in HRQoL remained unexplained, suggesting that there may be relevant determinants of HRQoL that were not considered in this analysis.

The most important determinants of the patients' satisfaction with mobility appeared to be their perception of their own physical health as well as mental health symptoms in their children. Significantly associated with self-care was the patients' psychopathology. Usual activities (e.g., work, study, housework, family or leisure activities) and pain/discomfort were primarily related to the patients' psychopathology and physical well-being. Feelings of anxiety/depression were mainly associated with the patients' psychopathology and child psychopathology. Parents with mental illness reported higher satisfaction with specific aspects of HRQoL when they felt physically and mentally well. Mental health symptoms in children were associated with any mobility-related problems as well as problems with anxiety and depression. The consideration of solely the most relevant determinants of HRQoL, identified through backward-elimination during regression analyses, slightly improved the amount of explained variance for global HRQoL, but slightly decreased the amount of explained variance in domain-specific outcomes. Risk and protective factors associated with specific HRQoL explained in final models 12% of variance in mobility, 14% in self-care and in usual activity, 19% in pain/discomfort, and 12% of variance in anxiety/depression. Parental coping behavior, whether it was adaptive or maladaptive, family functioning, social support, the patients' age and gender did not contribute to any of the domain-specific models.

Table 6. Risk and protective factors associated with global HRQoL of parents with mental illness

	EQ5D Index		EQ5D VAS	
Model	1[a]	2[b]	1[a]	2[b]
Fixed Effects	*b*	*b*	*b*	*b*
Physical health[1]	-0.24***	-0.22***	-0.17**	-0.16**
Psychopathology[2]	-0.56***	-0.54***	-0.46***	-0.47***
Parental Coping[3]				
Adaptive	0.09	0.10	0.22***	0.23***
Maladaptive	0.01		0.04	
Family functioning[4]	0.01		-0.01	
Social support[5]	0.04		0.06	
Child psychopathology[6]	0.04		-0.02	
Age[1]	-0.08		0.06	
Female[1]	-0.10		0.01	
Age by gender[1]	0.15		-0.05	
Model Fit				
Adjusted R^2	.39	.40	.33	.35

Note. *n* = 200. *b* = unstandardized coefficients; measures: [1] ad-hoc items, [2] BSI [3] FQCI, [4] FB-A, [5] OSSS-3, [6] CBCL 4-18; [a] Model 1 contains all factors, [b] Model 2 contains factors with p < .100 identified with backward elimination; all continues factors were mean-centered; analyses were conducted with multiple linear regression analyses and were based on raw data; for details see text (Methods). **p* < .05; ***p* < .01; ****p* < .001

Table 7. Risk and protective factors associated with domain-specific HRQoL of parents with mental illness

	Mobility				Self-Care				Usual Activity			
Model	1		2		1		2		1		2	
Fixed Effects	*B*	Exp(B)	*B*	Exp(B)	*B*	Exp(B)	*B*	Exp(B)	*B*	Exp(B)	*B*	Exp(B)
Intercept	-0.36*		-0.70**	0.50	-0.18	0.84	-0.83***	0.46	1.51**	4.51	1.14***	3.11
Physical health^1	-1.40**	0.25	-1.45***	0.24	-0.77*	0.46	-0.57	0.50	-0.75*	0.47	-0.67*	0.51
Psychopahtology^2	0.61	1.84			0.86**	2.37	0.91**	2.42	1.18**	3.24	1.12***	3.07
Parental Coping^3												
Adaptive	-0.08	0.92			-0.06	0.95			-0.38	0.68		
Maladaptive	-0.51	0.60			-0.23	0.80			-0.29	0.75		
Family functioning^4	-0.01	0.99			0.02	1.02	0.02	1.02	-0.03	1.01		
Social support^5	-0.09	0.92			-0.14	0.87			0.00	1.00		
Child psychopathology^6	0.02*	1.02	0.02**	1.02	0.01	1.01			0.00	1.00		
Age ^{1}	-0.06	0.94			0.10	1.01			0.06	1.06		
Female^1	-0.57	0.56			-0.75	0.47			-0.32	0.73		
Age by gender^1	0.05	1.05			-0.06	0.95			-0.05	0.95		
Model Fit												
R^2 (Cox & Snell)	.15		.12		.16		.14		.16		.14	

Note. n = 200. B = standardized coefficients; measures: ^{1} ad-hoc items, ^{2} BSI ^{3} FQCI ^{4} FB-A ^{5} OSSS-3, ^{6} CBCL 4-18 GSI; all continues factors were mean-centered; analyses were conducted with logistic regression and were based on raw data; for details, see text (Methods). *p < .05; **p < .01; ***p < .001

Table 8. Risk and protective factors associated with domain-specific HRQoL of parents with mental illness

	Pain/ Discomfort				Anxiety/ Depression			
Model	1		2		1		2	
Fixed Effects	*B*	*Exp(B)*	*B*	*Exp(B)*	*B*	*Exp(B)*	*B*	*Exp(B)*
Intercept	2.10***	8.14	1.92***	6.82	-0.36	0.67	-0.70**	0.50
Physical health^1	-1.80***	0.17	-1.70***	0.18	-1.40**	0.25	-1.45***	0.24
Psychopahtology^2	0.70	2.01	0.81**	2.25	0.61*	1.84		
Parental Coping^3								
Adaptive	-0.47	0.63	-0.51	0.60	-0.08	0.92		
Maladaptive	-0.08	0.93			-0.51	0.60		
Family functioning^4	-0.01	0.99			-0.01	0.99		
Social support^5	-0.15	0.87			-0.09	0.92		
Child psychopathology^6	0.01	1.01			0.02*	1.02	0.02**	1.02
Age ^{1}	0.10	1.10			-0.06	0.94		
Female^1	-0.03	0.97			-0.57	0.56		
Age by gender^1	-0.09	0.92			0.05	1.05		
Model Fit								
R^2 (Cox &Snell)	.22		.19		.15		.12	

Note. *n* = 200. *B* = standardized coefficients; measures: ^{1} ad-hoc items, ^{2} BSI ^{3} FQCI ^{4} FB-A ^{5} OSSS-3, ^{6} CBCL 4-18 GSI; all continues factors were mean-centered; analyses were conducted with logistic regression and were based on raw data; for details, see text (Methods). *p < .05; **p < .01; ***p < .001

5.2. HRQoL of COPMI

5.2.1. Average HRQoL of COPMI in Comparison to the General Population

Children belonging to the same family were more correlated than children from different families (ICC ≥ .10). In consequence, family clusters were considered in linear mixed models. The average HRQoL values self- and proxy-reported by children, their parents with mental illness and partners are displayed in *Table 9 - 11* respectively. Compared to the European reference sample with a mean of $M = 50$ and a standard deviation of $SD = 10$ (Ravens-Sieberer, 2006), parents with mental illness, their children and partners reported lower global (KIDSCREEN-10 index) and domain-specific child HRQoL (KISCREEN-27 subscales). From the parents with mental illness' perspective, the differences between the sample and the reference population were significant for global HRQoL and all domain-specific HRQoL outcomes, except for autonomy and parents (all other $p < .01$). From the children's perspective, group differences were significant for global HRQoL as well as for physical and mental health. The partner viewed differences between their proxy-reports and the those of the general population as significant with regard to global HRQoL and for the subscales physical and mental health (all $p < .01$). Parents with mental illness proxy-reported the lowest average HRQoL values for mental and physical health and the highest for autonomy and parents. The results indicate that parents with mental illness believe that their children's psychological and physiological well-being are particularly impaired, followed by dissatisfaction within the school and social setting and is least impaired regarding child-parent relationships and autonomy. Parents with mental illness tend to proxy-report lower HRQoL than the children regarding both global and domain-specific aspects, except for physical well-being. From the partners' perspective, domain-specific HRQoL was significantly reduced for the children's psychological and physical well-being, followed by social support and peers. Although partners assessed school-related quality of life of their offspring lower than did parents from the general population, those differences were not significant. In contrast to all other aspects of HRQoL, partners rated the subscale autonomy and parents slightly higher than the reference populations, suggesting that partners believe that the children have a positive relationship with parents and have enough financial resources and age-appropriate freedom to choose things for themselves. The results suggest that children and both parents agree that overall HRQoL of COPMI is reduced compared to the reference population with main impairments observed in psychological and physical aspects. Despite those observations, the ratings of both children and both parental units still indicate a medium HRQoL rating (Ravens-Sieberer, 2006).

Table 9. Average HRQoL of children from the perspective of the mentally ill parent

	Model-Based		
	Adjusted Mean	95% CI	ICC
KIDSCREEN-27 Subscale			
Physical well-being	43.81***	[42.42, 45.22]	.25
Mental health	43.04***	[41.05, 45.04]	.13
Autonomy and parents	48.61	[47.03, 50.20]	.71
Social support and peers	46.63**	[44.75, 48.51]	.41
School environment	46.94**	[45.18, 48.70]	.25
KIDSCREEN-10 Index	44.09***	[42.57, 45.61]	.40

Note. *n* = 189. CI = confidence interval, ICC = intraclass correlation coefficient; calculations were based on average T-scores and analyzed with a linear mixed model, for details, see text (Methods). **p* < .05; ***p* < .01; ****p* < .001

Table 10. Average HRQoL of children from the perspective of the child

	Model-Based		
	Adjusted Mean	95% CI	ICC
KIDSCREEN-27 Subscale			
Physical well-being	43.23***	[41.69, 44.78]	.27
Mental health	46.41**	[44.39, 48.43]	.33
Autonomy and parents	49.57	[47.79, 51.34]	.16
Social support and peers	48.27	[46.42, 50.12]	n.a.[1]
School environment	49.13	[47.30, 50.97]	.16
KIDSCREEN-10 Index	47.42**	[45.59, 49.25]	.33

Note. *n* = 136. CI = confidence interval, ICC = intraclass correlation coefficient; calculations were based on average T-scores and analyzed with a linear mixed model, for details, see text (Methods). [1] The ICC could not be estimated and was thus set to zero. **p* < .05; ***p* < .01; ****p* < .001

Table 11. Average HRQoL of children from the perspective of the partner

	Model-Based		
	Adjusted Mean	95% CI	ICC
KIDSCREEN-27 Subscale			
Physical well-being	43.99***	[42.30, 45.68]	.52
Mental health	45.34***	[42.98, 47.70]	.61
Autonomy and parents	51.06	[49.05, 53.07]	.73
Social support and peers	47.20*	[45.05, 49.36]	.35
School environment	48.35	[46.22, 50.49]	.44
KIDSCREEN-10 Index	46.11***	[44.28, 47.95]	.62

Note. *n* = 141. CI = confidence interval, ICC = intraclass correlation coefficient; calculations were based on average T-scores and analyzed with a linear mixed model, for details, see text (Methods). [1] The ICC could not be estimated and was thus set to zero. **p* < .05; ***p* < .01; ****p* < .001

5.2.2. Risk and Protective Factors Associated with HRQoL of COPMI

Table 12 displays the impact of various risk and protective factors on global HRQoL of children and adolescents aged 8-18 years from the mentally ill parent's perspective. As children within families were more closely related than children from different families (ICC = .45), family clusters were considered in linear mixed models. The model fit significantly improved by adding the risk and protective factors to the null model (χ^2(df) = 98.98 (12), $p < .001$). Child psychopathology, social support, the child's age, and parental psychopathology were significantly related with global HRQoL from the parents with mental illness' perspectives (all $p < .05$). On average, children showed lower HRQoL when they or their parents had mental health symptoms, when children were of older age, and when their parents with mental illness believed that their children receive little social support. In the final model, child-related determinants of HRQoL explained 53.41% of the residual variance in the outcome while family-related determinants explained only 6.23%. A significant amount of variation could not be explained by the information included, suggesting that there may be additional determinants of HRQoL.

The association between various risk and protective factors and global HRQoL of children and adolescents aged 8-18 years from the child's perspective is presented in *Table 13*. Family clusters were considered in linear mixed models as the ICC value equaled .26. The fit of the model improved when risk and protective factors were included (χ^2(df) = 54.56 (12), $p < .001$). From the perspective of the children, their perceived overall HRQoL was significantly associated with their mental health, social support and family functioning (all $p < .01$). Children reported lower HRQoL when they had mental health symptoms and when families had dysfunctional pattern. Social support had a protective effect as children with high levels of social support reported higher overall HRQoL. In the final model, child-related determinants of HRQoL explained 37.45% of the residual variance while family-related determinants explained 20.69%. A significant amount of variation could not be explained by the information included, suggesting that there may be additional determinants of HRQoL.

The association of child- and family related risk and protective factors on global HRQoL of children and adolescents from the partner's perspective is presented in *Table 14*. Family clusters were considered in linear mixed models as the ICC value equaled .45. The addition of various HRQoL determinants to the null model significantly improved the model fit (χ^2(df) = 27.06 (12), $p < .005$). Child psychopathology, social support, the child's age, and a parental coping style characterized by distraction and self-growth were significantly related with global HRQoL from the partners' perspectives (all $p < .05$). The children showed on average lower global HRQoL when they had mental health symptoms, when children were of older age and had little social support, and when parents with mental illness used distraction and self-growth to cope with distress. In contrast to the parents with mental illness' perspective but in line with the children's self-reports, parental psychopathology was not significantly related to the outcome. Child-related determinants of HRQoL explained 47.48% of the variance in the final model while family-related determinants explained only 7.46%. A significant amount of variation could not be explained by the information included, suggesting that there may be additional factors exerting an influence on HRQoL.

Table 12. The association of risk and protective factors with global HRQoL of children and adolescents aged 8-18 years from the perspective of the mentally ill parent

	Model	
	Coefficients	*SE*
Fixed Effects		
Intercept (KIDSCREEN-10, index)[1]	30.06***	0.49
Child-related predictors[1]		
Child psychopathology (CBCL 4-18, total score)	- 0.09***	0.01
Social support (OSSS-3, total score)	0.72***	0.15
Female	0.94	0.62
Age (years)	- 0.37*	0.15
Age by gender	0.10	0.19
Family-related predictors[1]		
Parental psychopathology (BSI, GSI)	- 1.62**	0.61
Family functioning (FB-A, total score)	- 0.04	0.03
Parents with mental illness’ coping (FQCI)		
Depressed processing style	0.09	0.11
Active problem-oriented coping	- 0.07	0.11
Distraction and self-growth	- 0.22	0.13
Religiosity an quest for meaning	0.00	0.11
Trivialization and wishful thinking	0.16	0.13
Random Effects		
Variance of residuals	9.66***	1.98
Variance of intercepts	7.76**	2.56
ICC	.45	
Model Fit		
Deviance	1047.44	
χ^2(df)	98.98 (12)***	
BIC	1057.71	

Note. *n* = 183. [1] based on the mentally ill parents’ self- and proxy-reports. *SE* = standard error, ICC = intraclass correlation coefficient, χ^2(df) = chi-squared (degrees of freedom), BIC = bayesian information criterion; all calculations were based on raw data and analyzed with a linear mixed model; all metric predictors were mean-centered; for details, see text (Methods). **p* < .05; ***p* < .01; ****p* < .001

Table 13. The association of risk and protective factors with global HRQoL of children and adolescents aged 8-18 years from the perspective of the child

	Model	
	Coefficients	*SE*
Fixed Effects		
Intercept (KIDSCREEN-10, index)[2]	42.94***	1.31
Child-related predictors		
Child psychopathology (YSR, total score)[2]	-0.11***	0.02
Social support (OSSS-3, total score)[2]	0.75***	0.21
Female[1]	-1.88	1.11
Age (years)[1]	-0.43	0.29
Age by gender[1]	0.13	0.37
Family-related predictors		
Parental psychopathology (BSI, GSI)[1]	0.76	0.86
Family functioning (FB-A, total score)[2]	-0.11**	0.04
Parents with mental illness' coping (FQCI)[1]		
Depressed processing style	-0.20	0.17
Active problem-oriented coping	0.03	0.16
Distraction and self-growth	0.11	0.18
Religiosity and quest for meaning	-0.13	0.15
Trivialization and wishful thinking	0.13	0.18
Random Effects		
Variance of residuals	18.73***	5.07
Variance of intercepts	6.76	5.47
ICC	.26	
Model Fit		
Deviance	794.30	
χ^2(df)	54.56 (12)***	
BIC	803.82	

Note. n = 136. [1] based on the mentally ill parent' self- and proxy-reports. [2] based on the child's self-report. *SE* = standard error, ICC = intraclass correlation coefficient, χ^2(df) = chi-squared (degrees of freedom), BIC = bayesian information criterion; all calculations were based on raw data and analyzed with a linear mixed model; all metric predictors were mean-centered; for details, see text (Methods). $^*p < .05$; $^{**}p < .01$; $^{***}p < .001$

Table 14. The association of risk and protective factors with global HRQoL of children and adolescents aged 8-18 years from the perspective of the partner

	Model	
	Coefficients	*SE*
Fixed Effects		
Intercept (KIDSCREEN-10, index)[2]	37.51***	0.61
Child-related predictors		
Child psychopathology (CBCL 4-18, total score)[2]	-0.06**	0.02
Social support (OSSS-3, total score)[2]	0.91***	0.20
Female[1,a]	0.59	0.78
Age (years)[1,a]	-0.38*	0.18
Age by gender[1,a]	0.14	0.24
Family-related predictors		
Parental psychopathology (BSI, GSI)[1]	-1.02	0.78
Family functioning (FB-A, total score)[2]	-0.10	0.07
Parents with mental illness' coping (FQCI)[1]		
Depressed processing style	0.10	0.14
Active problem-oriented coping	-0.07	0.15
Distraction and self-growth	-0.32*	0.16
Religiosity and quest for meaning	0.05	0.14
Trivialization and wishful thinking	0.26	0.16
Random Effects		
Variance of residuals	10.10***	2.16
Variance of intercepts	8.25**	2.83
ICC	.45	
Model Fit		
Deviance	706.98	
χ^2(df)	27.06 (12)*	
BIC	716.38	

Note. *n* = 134. [1] based on the mentally ill parent' self- and proxy-reports. [2] based on the partner/caregiver's proxy-report. [a] ad-hoc items. *SE* = standard error, ICC = intraclass correlation coefficient, χ^2(df) = chi-squared (degrees of freedom), BIC = bayesian information criterion; all calculations were based on raw data and analyzed with a linear mixed model; all metric predictors were mean-centered; for details, see text (Methods). *$p < .05$; **$p < .01$; ***$p < .001$

5.2.3. Child-Parent Reliability on the KIDSCREEN-27/10

The agreement between children and their parents with mental illness as well as between children and partners regarding global and domain-specific child HRQoL are displayed in *Table 15* – *Table 16* respectively. The interrater reliability between children and parents with mental illness reached significance for all aspects of HRQoL of COPMI (all $p < .001$). Interrater reliability was lowest for social support and peers and highest for school environment, reflected by ICC values between .34 and .49, respectively. The results indicate fair congruence between children and their parents with mental illness. The agreement between children and partners regarding global child HRQoL was lower than the agreement between children and their parents with mental illness. Nevertheless, interrater reliability between children and partners was significant for all global and specific aspects of child HRQoL except for the subscale autonomy and parents (all $p < .05$). Results indicate that the child's perspective deviates from the partner's perspective with regard to the quality of child-parent relationship, financial resources and the child's perceived level of autonomy. Agreement between children and partners was highest for mental health. Compared to the parents with mental illness, partners had relatively low agreement with their children regarding the children's satisfaction in the school setting, although the agreement was still significant.

Table 17 displays the determinants of total disagreement between children and parents with a mental illness regarding global child HRQoL. Overall, parents with mental illness rated their offspring's HRQoL lower than the children did. The seven determinants of child HRQoL explained 19.5% of the variance in the outcome. When the effects of all determinants were held constant, children and their parents with mental illness show $b = 3.84$ deviation points. Disagreement was significantly associated with the children's mental health and gender (all $p < .05$). The ratings deviated less from each other when children were male and had mental health symptoms. The children's age, family functioning, parents' psychopathology and HRQoL did not contribute to the model.

The association of various factors with total disagreement between children and partners regarding global child HRQoL is displayed in *Table 18*. In accordance with parents with mental illness, partners rated the children's global HRQoL lower than did the children. The determinants of child HRQoL included in the final model explained 18.8% of the variance in the outcome. When the effects of all included factors were held constant, children and their partners show b = 7.52 deviation points. Total disagreement was significantly associated with the child's gender and family functioning. Ratings deviated less from each other when children were male when family functioning was high. Child psychopathology, the age of the child, the partner's quality of life, and psychopathology of the mentally ill parent did not contribute to the model.

Table 15. Agreement between children and their parents with mental illness regarding HRQoL of children and adolescents aged 8-18 years

	ICC Consistency	ICC Absolute Agreement
	ICC [95% CI]	ICC [95% CI]
KIDSCREEN-27 Subscale		
Physical well-being	.46*** [.31, .59]	.46*** [.31, .59]
Mental health	.45*** [.30, .58]	.43*** [.28, .56]
Autonomy and parents	.42*** [.26, .55]	.42*** [.26, .55]
Social support and peers	.40*** [.24, .54]	.34*** [.13, .51]
School environment	.49*** [.35, .61]	.49*** [.35, .61]
KIDSCREEN-10 Index	.46*** [.31, .59]	.45*** [.30, .58]

Note. *n* = 127. CI = confidence interval, ICC = intraclass correlation coefficient; for details, see text (Methods). **p* < .05; ***p* < .01; ****p* < .001

Table 16. Agreement between children and partners regarding HRQoL of children and adolescents aged 8-18 years

	ICC Consistency	ICC Absolute Agreement
	ICC [95% CI]	ICC [95% CI]
KIDSCREEN-27 Subscale		
Physical well-being	.41*** [.24, .57]	.42*** [.24, .57]
Mental health	.42*** [.26, .55]	.42*** [.26, .55]
Autonomy and parents	.06 [-.14, .25]	.06 [-.14, .26]
Social support and peers	.35*** [.16, .51]	.35*** [.16, .51]
School environment	.35*** [.16, .51]	.35*** [.16, .51]
KIDSCREEN-10 Index	.23* [.03, .40]	.23* [.03, .41]

Note. *n* = 98. CI = confidence interval, ICC = intraclass correlation coefficient; for details, see text (Methods). **p* < .05; ***p* < .01; ****p* < .001

Table 17. Determinants of disagreement between children and their parents with mental illness regarding global HRQoL of children and adolescents aged 8-18 years

Fixed Effects	b	*SE*
Intercept (KIDSCREEN-10 index)	3.84*	1.88
Child-related predictors[1]		
Child psychopathology (CBCL 4-18, total score)	-0.05*	0.02
Female[1,a]	-3.88**	1.21
Age (years) [1,a]	0.78	0.63
Age by gender[1,a]	-0.42	0.42
Family-related predictors[1]		
Family functioning (FB-A, total score)	-0.05	0.04
Parental health-related quality of life (EQ-5D-3L, total score)	5.37	3.16
Parental psychopathology (BSI, GSI)	0.98	1.13

Note. *n* = 124, F (7, 116) = 5.25***. Model fit: adjusted R^2 = 19.5%. [1] based on the mentally ill parent' self- and proxy-reports. [a] ad-hoc items. b = unstandardized coefficient *SE* = standard error. All calculations were based on raw data and analyzed with a linear mixed model; all metric predictors were mean-centered; for details, see text (Methods). **p* < .05; ***p* < .01; ****p* < .001

Table 18. Determinants of disagreement between children and partners regarding global HRQoL of children and adolescents aged 8-18 years

Fixed Effects	b	*SE*
Intercept (KIDSCREEN-10 index)[2]	7.52**	2.64
Child-related predictors		
Child psychopathology (CBCL 4-18, total score)[2]	-0.04	0.04
Female[1,a]	-5.81**	1.76
Age (years) [1,a]	0.16	0.92
Age by gender[1,a]	-0.09	0.62
Family-related predictors		
Family functioning (FB-A, total score)$_2$	-0.33*	0.13
Parental health-related quality of life (EQ-5D-3L, total score)[2]	11.07	5.72
Parental psychopathology (BSI, GSI)[1]	0.53	1.11

Note. *n* = 94, F (7, 81) = 3.91***. Model fit: adjusted R^2 = 18.8%. [1] based on the parents with mental illness' self- and proxy-reports. [2] based on the partner/caregiver's proxy-report. [a] ad-hoc items. b = unstandardized coefficient *SE* = standard error. All calculations were based on raw data and analyzed with a linear mixed model; all metric predictors were mean-centered; for details, see text (Methods). **p* < .05; ***p* < .01; ****p* < .001

5.3. HRQoL of Partners of Parents with Mental Illness

5.3.1. Average HRQoL of Partners in Comparison to the General Population

Table 19 presents the self-reported global and specific HRQoL ratings of n = 141 partners in comparison to the German reference population after age standardization (Janssen et al., 2019). The differences in proportions of respondents scoring any problem with mobility, self-care, usual activities, pain/discomfort, and anxiety/depression are displayed together with the EQ-5D-3L VAS and the EQ-5D-3L index that measure partners' overall HRQoL. Partners self-reported significantly lower global HRQoL on the EQ-5D-3L index ($p < .001$) but not on the EQ-5D-3L VAS. In contrast to the general population, a significantly higher proportion of partners self-reported any problems with usual activities, pain/discomfort, and anxiety/depression (all $p < .001$). The deviation in HRQoL from the reference population was most pronounced in the HRQoL domains anxiety and depression followed by pain/discomfort, and usual activities. Differences between the sample and the reference population were not significant regarding the HRQoL aspects mobility and self-care, for which the proportion of people reporting any problems was even smaller in this sample.

Table 19. Self-reported HRQoL scores after age standardization, mean EQ VAS, EQ Index and proportions (%) of respondents scoring any problem

EQ-5D-3L	German Population Norms	Sample	*p*
Mobility	17.2%	15.6% [10.0, 22.7]	.35
Self-care	3.1%	2.8% [0.8, 7.1]	.500
Usual activities	10.5%	20.6% [14.2, 28.2]	< .001***
Pain/ discomfort	27.8%	50.4% [41.8, 58.9]	< .001***
Anxiety/depression	4.5%	32.6% [25.0, 41.0]	< .001***
VAS	M = 77.2	M = 74.76 [71.58, 77.93]	.13
Index	M = 0.90	M = 0.81 [0.79, 0.84]	< .001***

Note. n = 141. Square brackets indicate the 95% confidence interval; for details see text (Methods). *$p < .05$; **$p < .01$; ***$p < .001$

5.3.2. Risk and Protective Factors Associated with HRQoL of Partners

The associations of multiple risk and protective factors with global HRQoL of partners are displayed in *Table 20*. Those of the domain-specific HRQoL are displayed in *Table 21* – *Table 22*. The most important factors associated with global HRQoL of partners were the respondents' physical and psychopathology, social support and their gender. In addition, the EQ-5D-3L index was significantly associated with family functioning, respondents' age and the interaction of age and gender, whereas the EQ-5D-3L was significantly associated with respondents' maladaptive coping behavior and gender. Regarding the most relevant HRQoL determinants shared by both global HRQoL measures, partners reported higher overall HRQoL when they were in good physical and mental condition, when they reported high levels of social support, and when they had a male gender. The significant HRQoL determinants explained 48% of the variance in the EQ-5D-3L index and 54% of the variance in the EQ-5D-3L VAS. Adaptive coping and child psychopathology did neither contribute to the model of the EQ-5D-3L index nor the EQ-5D-3L VAS. Approximately half of the variance in global HRQoL remained unexplained, suggesting that there may be additional relevant factors that were not considered in this analysis.

Factors that were significantly associated with mobility problems from the perspective of the partner appeared to be their physical and mental health, adaptive and maladaptive coping behavior, and social support. Partners where more likely to be satisfied with their mobility when they were in good physical and mental condition, and when they had high levels of social support. Frequent adaptive coping behavior was associated with a higher occurrence of any mobility problems, whereas maladaptive coping had the opposite effect. Because almost all partners (95%) stated that they had no problems with self-care, no meaningful association could be established between risk and protective factors that were associated with any self-care related problems. Satisfaction with usual activities such as work, study, housework, family or leisure activities was significantly related to a good physical and mental health. Pain and discomfort were significantly associated with partners' physical health, maladaptive coping behavior, social support and gender. Having no problems with pain and discomfort was more likely when partners were in good physical condition, when they seldom used maladaptive coping strategies and felt socially supported and when they were male. Having no problems with anxiety and depression was significantly associated with good physical health and high levels of social support. Including only the most relevant HRQoL of the final model slightly increased the amount of explained variance in global HRQoL (EQ-5D index) but decreased the amount of explained variance in all domain-specific outcomes. Risk and protective factors associated with domain-specific HRQoL explained 24% of variance in mobility, 22% in usual activity, 35% in pain/discomfort, and 15% of variance in anxiety/depression in final models. Family functioning, child psychopathology, and partners' age did not contribute to any of the domain-specific final models.

Table 20. Risk and protective factors associated with global HRQoL of partners

	EQ5D Index		EQ5D VAS	
Model	1[a]	2[b]	1[a]	2[b]
Fixed Effects	*B*	*B*	*B*	*B*
Physical health[1]	-0.15*	-0.18**	-0.25***	-0.28***
Psychopathology (BSI GSI)	-0.41***	-0.40***	-0.46***	-0.43***
Parental Coping (FQCL total score)				
Adaptive	-0.08		-0.36	
Maladaptive	-0.11	-0.13	-0.17*	-0.16*
Family functioning (FB-A total score)	0.14*	0.14*	0.07	
Social support (OSSS-3 total score)	0.28***	0.28***	0.16*	0.14*
Child psychopathology (CBCL 4-18 total score)	-0.03		0.06	
Age[1]	0.54*	0.52*	-0.31	
Female[1]	0.12	0.14*	0.16*	0.17**
Age by gender[1]	-0.62*	-0.60*	0.25	
Model Fit				
Adjusted R^2	.47	.48	.54	.54

Note. *n* = 139. *b* = standardized coefficients; measures: [1] ad-hoc items. [a] Model 1 contains all factors, [b] Model 2 contains factors with p < .100 identified with backward elimination; all continues factors were mean-centered; analyses were conducted with multiple linear regression analyses and were based on raw data self-reported by partners; for details see text (Methods). *$p < .05$; **$p < .01$; ***$p < .001$

Table 21. Risk and protective factors associated with domain-specific HRQoL of partners

	Mobility				Self-Care[a]				Usual Activity			
Model	1		2		1		2		1		2	
Fixed Effects	*B*	Exp(B)	*B*	Exp(B)	*B*	Exp(B)	*B*	Exp(B)	*B*	Exp(B)	*B*	Exp(B)
Intercept	-1.23**	0.29	-1.36***	0.26	-	-	-	-	-0.55	0.58	-0.49	0.61
Physical health[1]	-1.12	0.33	-1.26*	0.28	-	-	-	-	-1.46**	0.08	-1.49**	0.23
Psychopahtology[2]	1.83**	6.23	1.72**	5.57	-	-	-	-	1.86**	6.44	2.12***	8.34
Parental Coping[3]					-	-	-	-				
Adaptive	1.60**	4.94	1.30**	3.67	-	-	-	-	0.38	1.46		
Maladaptive	-1.65**	0.19	-1.51**	0.22	-	-	-	-	0.15	1.16		
Family functioning[4]	0.01	1.01			-	-	-	-	0.02	1.02		
Social support[5]	-0.26*	0.77	-0.25*	0.78	-	-	-	-	-0.10	0.90		
Child psychopathology[6]	0.01	1.01			-	-	-	-	-0.03	0.97	-0.02	0.98
Age [1]	-0.03	0.97			-	-	-	-	-0.20	0.82		
Female[1]	-0.96	0.38			-	-	-	-	-0.33	0.73		
Age by gender[1]	0.01	1.01			-	-	-	-	0.10	1.10		
Model Fit												
Adjusted R^2 (Cox & Snell)	.26		.24		-		-		.25		.22	

Note. *n* = 139. *B* = unstandardized coefficients; measures: [a] Self-care could not be analyzed due to disproportionate sample size differences in subgroups (only 5.0% of the participants reported any problems). [1] ad-hoc items, [2] BSI GSI, [3] FQCI, [4] FB-A total score [5] OSSS-3 total score, [6] CBCL 4-18 total score. All continues factors were mean-centered; analyses were conducted with logistic regression and were based on raw data self- reported by partners; for details, see text (Methods). **p* < .05; ***p* < .01; ****p* < .001

Table 22. Risk and protective factors associated with domain-specific HRQoL of partners

	Pain/ Discomfort				Anxiety/ Depression			
Model	1		2		1		2	
Fixed Effects	*B*	*Exp(B)*	*B*	*Exp(B)*	*B*	*Exp(B)*	*B*	*Exp(B)*
Intercept	1.64**	5.13	1.38**	3.91	-1.23**	0.29	-0.90**	0.41
Physical health[1]	-2.27***	0.10	-2.11***	0.12	-1.12	0.33	-1.57**	0.21
Psychopahtology[2]	0.77	2.17			1.83**	6.23		
Parental Coping[3]								
Adaptive	-0.25	0.78			1.60**	4.94		
Maladaptive	1.69**	5.40	1.54**	4.64	-1.65**	0.19		
Family functioning[4]	-0.02	0.98			0.01	1.01		
Social support[5]	-0.42***	0.66	-0.39***	0.68	-0.26*	0.77	-0.24**	0.79
Child psychopathology[6]	-0.01	1.00			0.01	1.01		
Age [1]	0.27	1.32			-0.03	0.97		
Female[1]	1.09*	2.98	0.96*	2.62	-0.96	0.38		
Age by gender[1]	-0.15	0.86			0.01	1.01		
Model Fit								
Adjusted R^2 (Cox &Snell)	.38		.35		.26		.15	

Note. *n* = 139. *B* = unstandardized coefficients; measures: [1] ad-hoc items, [2] BSI GSI, [3] FQCI, [4] FB-A [5] OSSS-3, [6] CBCL 4-18; all continues factors were mean-centered; analyses were conducted with logistic regression and were based on raw data self- reported by partners; for details, see text (Methods). **p* < .05; ***p* < .01; ****p* < .001

5.5 The Link Between Family Members' HRQoL

Pearson correlations between total scores of family members' overall HRQoL are shown in *Table 23*. Each family member (parents with mental illness, children, partners) self-reported HRQoL. In addition, both parental proxy-reports of child HRQoL were included. The HRQoL of parents with mental illness was significantly positively related to child HRQoL (proxy-reported by mentally ill parent) and showed moderate correlations. Similarly, the HRQoL of partners was significantly positively correlated with the children's HRQoL (proxy-reported by either parent) although the coefficients indicate a weak association. The correlations suggest that higher HRQoL of children is association with higher HRQoL of both parents. In contrast, the HRQoL of parents with mental illness and partners assessed was significantly negatively associated when assessed with the EQ-5D-3L VAS suggesting that when one parent feels well, the other feels unwell. In contrast, parental HRQoL was almost unrelated when it was assessed with the EQ-5D-3L index. The correlations of parental and child HRQoL were only significant when HRQoL values were assessed from the same rater. Thus, the children's self-reported HRQoL had no significant correlations with either parent's HRQoL. Nevertheless, family members' perspectives on child HRQoL were significantly correlated indicating that family members had similar perceptions of children's current life satisfaction (all $p < .05$).

Table 23. Pearson correlations between family members' HRQoL

HRQoL	*M (SD)*	1	2	3	4	5	6	7
1. Parents with mental illness (self-report, EQ-5D-3L index)	0.56 (0.22)	-						
2. Parents with mental illness (self-report, EQ-5D-3L VAS)	54.22 (19.67)	.60***	-					
3. Children (self-report, KIDSCREEN-10 index)	37.84 (6.71)	-.01	.07	-				
4. Children (proxy-report by parents with mental illness, KIDSCREEN-10 index)	36.60 (5.70)	.16*	.20**	.46***	-			
5. Children (proxy-report by partners, KIDSCREEN-10 index)	37.74 (5.55)	-.09	-.08	.23*	.53***	-		
6. Partners (self-report, EQ-5D-3L index)	0.81 (0.16)	.07	-.32***	.00	.15	.32***	-	
7. Partners (self-report, EQ-5D-3L VAS)	74.76 (19.05)	-.06	-.22**	.10	.20*	.46***	.67***	-

Note. n = 208 parents with mental illness, *n* = 136 self-reports of child HRQoL, *n* = 189 parents with mental illness' proxy-reports of child HRQoL, *n* = 141 partners' proxy-reports of child HRQoL, *n* = 141 partners. $^*p < .05$; $^{**}p < .01$; $^{***}p < .00$

6. Discussion

6.1. HRQoL of Parents with Mental Illness

The first research objective aimed at comparing the HRQoL of parents with mental illness with the HRQoL of the general population. Moreover, the risk and protective factors that are associated with HRQoL of parents with mental illness were examined. Parents with mental illness self-reported significantly lower global and domain-specific HRQoL compared to the German general population (Janssen et al., 2019). They reported most dissatisfaction regarding the HRQoL domain anxiety and depression followed by usual activities, pain/discomfort, and self-care. In those HRQoL domains, the proportion of respondents who scored any problem was significantly higher in this sample than in the general population. Although the differences between the sample and the general population were also significant regarding the HRQoL domain mobility, they were smaller than in the other HRQoL domains. The global HRQoL of parents with mental illness was significantly associated with self-reported physical and mental health, as well as adaptive coping behavior. Parents with mental illness reported more satisfaction with global HRQoL when they had better physical and mental health, and when they used adaptive coping strategies such as active problem-oriented coping and distraction and self-growth to cope with stress resulting from their mental illness. The significant variables explained more than one third of the variance in the patients' global HRQoL. Maladaptive coping behavior, family functioning, social support, child psychopathology, the patients' age and gender did not contribute to the model describing global HRQoL. Regarding domain-specific HRQoL, mobility was significantly associated with the patients' self-reported physical health and child psychopathology. Significantly associated with self-care were the patient's mental health. Usual activities and pain/discomfort were significantly related to the patient's mental and physical health. Anxiety and depression were significantly associated with the patients' mental health and child psychopathology. Parents with mental illness reported lower HRQoL across domains when they had good physical and mental health. In addition, when children had mental health symptoms the parents with mental illness were more likely to report any problems with mobility or anxiety/depression. Risk and protective factors in final models explained 12-19% of the variance in the HRQoL domains. Parental coping behavior, family functioning, social support, the patients' age and gender did not contribute to any of the final models that described domain-specific HRQoL.

The finding that global HRQoL of parents with mental illness is significantly reduced compared to parents from the general population was in accordance with the prior hypotheses and previous studies (Comer et al., 2010; Kang et al., 2020; Krattenmacher et al., 2014; Law et al., 2005). Parents with mental illness in this sample reported mainly problems with the anxiety/ depression, usual activities, pain/ discomfort, and self-care, and less problems with mobility and self-care, which resembles the results of a study with 445 patients with social phobia (Sonntag et al., 2013). Several factors have been proposed to explain the decreased HRQoL in parents with mental illness. First of all, the mental illness can exacerbate parent's efforts to fulfill multiple role demands in the familial, social or occupational setting thereby elevating stress levels and decreasing the patients' HRQoL (Raitasalo & Holmila, 2017). In addition, parents with mental illness have an increased likelihood to face psychosocial adversities (e.g., poverty, unemployment housing insecurity), stressful life events (e.g., divorce, custody loss), organizational challenges (e.g., treatment adherence, meeting family appointments), insufficient social support, mental illness in their children, to live in dysfunctional families (e.g., conflicts, less family cohesion, disruption of family routine), and they are more likely to develop physical illness (Doherty & Gaughran, 2014; Freed et al., 2015; Gupta & Bowie, 2018; Kaplan et al., 2019; Luciano et al., 2014; McLaughlin et al., 2012; Vogt et al., 2017; Wang et al., 2016; Wiegand-Grefe et al., 2012). The latter was also observed by Krattenmacher et al. (2014) who compared the HRQoL of more than 60 German parents with mental illness with an equal number of somatically ill parents who had cancer diagnoses. The authors found that parents with mental illness can be as physically impaired as parents with cancer (Krattenmacher et al., 2014). Poor physical quality of life in people with mental illness can reflect a higher tendency to show somatic symptoms (Chander et al., 2019; Dreher et al., 2017) and to display health-impeding behaviors such as smoking, healthy dieting, regular exercise (Annamalai, Kosir, & Tek, 2017; Mulligan et al., 2018; Szatkowski & McNeill, 2015).

In this dissertation, the factors physical health, mental health and adaptive coping were identified as relevant HRQoL determinants of parents with mental illness. The magnitude and direction of this finding are in line with previous studies. Good physical (Fontaine & Barofsky, 2001; Strine, Chapman, Balluz, Moriarty, & Mokdad, 2008) and mental health (Comer et al., 2010; Dean, Gerner, & Gerner, 2004; Kang et al., 2020; Law et al., 2005) have been associated with better HRQoL. Adaptive coping strategies like active problem-oriented coping, social exchange, focus on one's strengths and positive attributes have been identified as a protective factors for one's physical and mental health (e.g., decreased symptom severity, shorter illness duration, less comorbidities, better adaption to mental illness), they can reduce the family burden and stigmatization, and improve the HRQoL of the parents with mental illness as well as the HRQoL of their families (Griva & Anagnostopoulos, 2010; Meyer, 2001; Peay et al., 2013; Ubel et al., 2010; van der Sanden, Pryor, Stutterheim, Kok, & Bos, 2016; Vollrath et al., 2003). Against the expectations and in contrary to previous research (Caron et al., 1998; Castelein et al., 2008; Foldemo et al., 2005; Maulik et al., 2010; Vasilopoulou & Nisbet, 2016; Wang et al., 2016), family functioning, social support, child-psychopathology and the patients' age and gender were not relevant for the HRQoL of parents with mental illness, here. It may be that the use of a different HRQoL measurement instrument enables future research to detect any effects of those factors on HRQoL. The items of the EQ-5D-3L focus primarily on physical rather than mental quality of life components. Thus, it provides a very limited coverage of themes that bother people with mental illness such as satisfaction with family relationships (Brazier et al., 2014). Moreover, the present sample included patients with rather severe mental symptoms and a considerable proportion of psychotic disorders. However, the utility of the EQ-5D-3L in mental health settings, especially regarding severe mental disorders and psychosis has been questioned by multiple researchers (Brazier, 2010; Mulhern et al., 2014; Papaioannou et al., 2011; Sonntag et al., 2013).

The patients' satisfaction with mobility was significantly associated with physical health and child psychopathology. Physical health is closely related to motor functions and the ability to move, which is important to lead an independent life (Mollaoğlu, Tuncay, & Fertelli, 2010). Child psychopathology may restrict the patients perceived mobility as children may require more attention, emotional and practical assistance. Parents may also have less time to take a walk because they must seek and manage the clinical appointments of their children. In accordance with other studies (Ciechanowski, Katon, Russo, & Hirsch, 2003; den Ouden, Schuurmans, Mueller-Schotte, Brand, & van der Schouw, 2013; Torales, Barrios, & González, 2017), any problems with self-care (e.g., washing, dressing) were significantly associated with the patients' mental health. For example, Ciechanowski et al. (2003) showed depressive symptoms among diabetes patients were associated with less self-care behaviors such as adherence to exercise regimes and diet. Another study reported that people with mental illness are at greater risk compared to the general population to suffer from dental diseases due to a lack of self-care and difficulties to access health services (Torales et al., 2017). People with severe mental illness can perceive the self-care activities that are part of the patients' treatment regimens as burdensome. Problems with self-care are more frequently reported by socially isolated people (Evert, Harvey, Trauer, & Herrman, 2003). It is surprising though that self-care was not significantly associated with the patients' physical health (den Ouden et al., 2013). It may be that the patients' physical impairments were not severe enough to impair self-care. Any problems with usual activities (e.g., work, study, housework, family, recreational activities) were significantly associated with the poor mental and physical health of the patients. The results are in line with past research showing that physical and mental illness can interfere with daily routines (Barile et al., 2012; den Ouden et al., 2013; Frost, Hristova, Steketee, & Tolin, 2013; Goetz et al., 2007). For example, a cross-sectional study with a total sample of 537 middle-aged and older participants examined domains that contribute to disability in activities of daily living. The results of multivariable logistic regression analysis showed that poor physical and mental health were significant predictors of disability in activities with daily living (den Ouden et al., 2013). In the present study, pain and discomfort were significantly related to the patients' mental and physical health. Support for the influence of physical health on pain/discomfort comes from multiple studies (Broen, Braaksma, Patijn, & Weber, 2012; Mirmosayyeb et al., 2020; Van Den Beuken-Van, Hochstenbach, Joosten, Tjan-Heijnen, & Janssen, 2016). The impact of mental health on pain/discomfort (e.g., shortness of breath, weakness) has been explained by patients’ tendencies to somaticize (Chander et al., 2019; Dreher et al., 2017). A meta-analysis found that people with bipolar disorder experience significantly increased levels chronic pain and headaches (Stubbs et al., 2015). Any problems with anxiety and depression were significantly related to worse physical health in patients as well as psychopathology in children. This is in line with studies that have detected a high prevalence of mental disorders in people who suffer from chronic physical impairments (Broen et. al., 2016; Salinero-Fort et al., 2018) and that have linked child psychopathology to decreased mental health and quality of life in caregivers (Foldemo et al., 2005; Vasilopoulou & Nisbet, 2016). Surprisingly, no significant relationship between the HRQoL domain anxiety/depression and the patients’ mental health could be established although there is evidence that the severity of mental health symptoms is closely related to the patients’ HRQoL (Watson et al., 2018). The large amount of unexplained variance of global and domain-specific HRQoL indicates that future research may focus on the identification and inclusion of other relevant factors that are associated with HRQoL of parents with mental illness.

6.2. HRQoL of COPMI

6.2.1. HRQoL Determinants of COPMI

One aim of the second research objective was to compare the HRQoL of COPMI with the HRQoL of the general population. To improve the quality of life of affected children and adolescents, this dissertation further aimed at the identification or risk and protective factors associated with child HRQoL. The association of various child- and family related predictors with overall child HRQoL was explored from both parents’ and the children’s perspectives. Moreover, the magnitude, direction and prediction of child-parent (dis)agreement was examined. In line with the expectations, children self- and parents proxy-reported significantly lower global HRQoL than the European reference population, although their ratings still indicated medium satisfaction with HRQoL (Ravens-Sieberer, 2006). Overall, both parents with mental illness and their partners reported lower overall HRQoL of children than their offspring, whereby the partners’ quality of life assessments resembled the child self-reports slightly more. All raters agreed that physical and mental health were the most impaired aspects of child HRQoL. Thus, compared to their peers, COPMI feel physically more exhausted and unwell, they experience fewer positive emotions, lower self-esteem, more loneliness and sadness. The least impaired HRQoL domains were autonomy and parents, and school environment indicating that children feel relatively positive about the relationship with parents as well as that they have the freedom, financial resources, and autonomy to do things they like. COPMI appeared to be relatively satisfied with their learning abilities and school environment. From both parents’ perspectives, child psychopathology, social support and the child’s age were significantly related with global child HRQoL. In addition, parents with mental illness viewed their own psychopathology as a relevant HRQoL determinant, while from the partners’ perspective the coping behavior of the parent with mental illness was significantly associated with child HRQoL. Significantly associated with overall

HRQoL from the perspective of the children were their own mental health, social support and family functioning. Children had lower HRQoL when they or their parents with mental illness experienced worse mental health, when children were of older age and received little social support, when families were characterized by dysfunctional patterns and when their parents with mental illness frequently used distraction and self-growth to cope with distress.

All in all, the results are in line with prior studies that reported lower HRQoL of COMPI and underreported HRQoL from the parents' perspective (Dey, Landolt, Mohler-Kuo, et al., 2013; Dittrich et. al., 2018; Ferro, Avison, Campbell, & Speechley, 2011; Giannakopoulos et al., 2009; Goetz et al., 2017; Hagen et al., 2019). Regarding domain-specific differences, more pronounced impairments in mental and physical health were also consistently reported in other studies (Hagen et al., 2019; Kayed et al., 2015; McLaughlin et al., 2012; Wiegand-Grefe et al., 2012; Yoo, Chung, & Lee, 2015). The elevated risk of mental illness in COPMI due to various genetic and environmental factors (Dey et al., 2012; Hosman et al., 2009; Weber et al., 2017b) has been associated with reduced child HRQoL (Barkmann et al., 2016; Jonsson et al., 2017). Physical impairments may represent the somatization of mental symptoms in terms of headaches, chest pain, nausea and fatigue (Silber, 2011). A Finnish retrospective population-based cohort study with more than 100.000 participants found that mother's substance abuse increased the children's risk of hospitalization for somatic illness (OR = 1.34) and mental illnesses (OR = 1.33) (Raitasalo & Holmila, 2017). Somatic symptoms in adolescence significantly predict severe adult mental illness as measured by hospital-based care even when controlling for sex, adolescent depression and anxiety (Bohman et al., 2018). The findings of this dissertation and the results of previous studies on somatization highlight the need to identify children at risk who experience mental or physical complaints and to refer them to early mental health consultation and treatment. With appropriate treatment, children and adolescents have a good prognosis for most somatization disorders (Silber, 2011). COPMI in the present sample were relatively satisfied with their granted level of autonomy, financial resources and the academic environment. Although no direct assessment of socioeconomic status has been conducted, families' sociodemographic characteristics (i.e., parents' high education and the presence of a second parental income in most families) suggest that children had no distanced economic disadvantage compared to their peers. Children in this study perceived their freedom and autonomy as adequate. In contrast some other studies reported that COMPI are granted either too low or too much autonomy. For example, children of parents with anxiety disorders have been found to be less autonomous (Gerull & Rapee, 2002), while some other children take on (too) high levels of care responsibilities for their parents with mental illness (Gray, Robinson, & Seddon, 2008).

Parents agreed that child psychopathology, social support and the child's age were significantly associated with global child HRQoL. Moreover, parents with mental illness viewed their psychopathology as a relevant factor contributing to child HRQoL. The partners rather emphasized the coping behavior of parents with mental illness, especially distraction and self-growth. From the children's perspective, their overall HRQoL was significantly associated with their mental health, social support and family functioning. Except for the negative association between coping by distraction and self-growth with child HRQoL, the magnitude and direction of the observed effects are in line with the majority of studies (Bastiaansen, Koot, Ferdinand, & Verhulst, 2004; Chu, Saucier, & Hafner, 2010; Cleaver & Unell, 2011; Jeske et al., 2009; Raffaelli et al., 2013; Ravens-Sieberer et al., 2007; Reupert et al., 2012; Sawyer et al., 2002; Wiegand-Grefe et. al., 2010). Inconsistent results have been reported for the direction and magnitude of parental distraction (distract oneself from uncomfortable emotions) and self-growth coping (indulge oneself more, search for positive self-affirming sense of achievements) on child quality of life and mental health. Only two predecessor studies of the CHIMPS project have investigated this association with the same coping questionnaire. Their correlational analyses showed neither a significant association between parents with mental illness' coping style distraction and self-growth and the mental health of the children nor with their quality of life (Jeske et al., 2009; Wiegand-Grefe et al., 2015). The direction of the correlation between distraction and self-growth and children's' quality of life was inconsistent across quality of life domains, but in contrast to the present results better overall child quality of life was associated with frequent parental distraction and self-growth coping (Jeske, Bullinger, & Wiegand-Grefe, 2010). One explanation for the inconsistent results may originate from the fact that the FQCI summarizes distraction and self-growth in one subscale while the two concepts may actually represent opposing constructs in terms of adaptive qualities. Another explanation may be that distraction and self-growth have not been clearly defined. In accordance with the present results, several studies detected that distraction coping is associated with more severe symptoms and poor functioning in individuals with posttraumatic stress disorder (Tull, Berghoff, Wheeless, Cohen, & Gratz, 2018; Woodward et al., 2020), psychosis (Piotrowski et al., 2020), and substance-use disorder (Caparrós & Masferrer, 2021). As individuals shift attention to another activity in order to avoid dealing with a problem situation (Rueda & Rothbart, 2009), distraction and withdrawal are facets of maladaptive avoidance coping (Dempsey, Stacy, & Moely, 2000). However, there may be one exception. When distraction coping is operationalized as seeking alternative or emotional discharge, or when distraction channels attention towards wellness behaviors (e.g., increase social contact, take a walk, do something fun), it can be an adaptive strategy for individuals with mental health symptoms (Marsac, Donlon, Winston, & Kassam-Adams, 2013; Tull et al., 2018; Woodward et al., 2020). Thus, whether distraction is considered an adaptive (positive distraction) or maladaptive (avoidance) strategy depends on its operationalization (Waugh, Shing, & Furr, 2020). In contrast to the prior stated hypotheses, the child's gender and its interaction with age, as well as parental coping did not contribute significantly to child HRQoL from either perspective, although the direction of the effects was compliant with other research (Green et al., 2010; Jeske et al., 2009; McLeod et al., 2007; Ravens-Sieberer, 2006; Ravens-Sieberer et al., 2007). Future research is needed to examine whether the non-significance reflects actual facts or whether it is attributable to overlap between predictors, the characteristics of the questionnaires or the sample or social desirability bias (Green et al., 2010; Jeske et al., 2009; McLeod et al., 2007; Ravens-Sieberer, 2006; Ravens-Sieberer et al., 2007). All in all, the results suggest that clinical interventions and policies should strengthen resilience in children of parents with mental illness and improve their quality of life primarily by alleviating mental distress in children, by increasing their supportive social network and by improving family functioning. The benefits of psychotherapy (Pu et al., 2017; Zeeck et al., 2018), peer support groups (Fraser et al., 2008; van Santvoort et al., 2014; Wiegand-Grefe et al., 2012), and family therapy (Wiegand-Grefe, Werkmeister, Bullinger, Plass, & Petermann, 2011) on quality of life in children at risk have been demonstrated by multiple studies including randomized controlled trials and meta analyses.

6.2.2. Child-Parent Reliability on the KIDSCREEN-27/10

Despite the benefits of child self-reports in quality of life assessments, parents' proxy-reports have often replaced the child's own perspective (Upton et al., 2008). As parents are sometimes asked to make clinical decisions on behalf of their minor children and because parents' proxy-reports on child HRQoL may be affected by mental disorders (Cremeens, Eiser, Blades, et al., 2006), it is important to examine the magnitude and direct on child-parent agreement in this population as well as to identify probable predictive factors for disagreement. The assessments of children and both parents showed fair congruence for most global and specific aspects of child HRQoL. The agreement between children and parents with mental illness was slightly lower compared to families of the general population (Ravens-Sieberer, 2006). This is consistent with previous research that reported higher informant discrepancies regarding child HRQoL or psychopathology when parents were distressed or had mental health symptoms (Bastiaansen et al., 2004; Janicke et al., 2007; Klassen et al., 2006; Kobayashi et al., 2011; White-Koning et al., 2007). In consequence, one may assume that the interrater reliability between children and healthy parents on overall HRQoL would be higher than the agreement with the parents with mental illness. However, the opposite is the case. It may be that the partners of parents with mental illness, who were mostly male, were less involved in child rearing than were the parents with mental illness. Thus, they may possess less child-related information that would enable them to make informed proxy assessments (Jensen et al., 1988; Treutler & Epkins, 2003; White-Koning et al., 2007). On the other hand, partners and parents with mental illness may vary in their awareness, sensitivity and tolerance of aspects that relate to child HRQoL and each can provide valuable sources of information. Because there is no ultimate true value of child HRQoL, self- and proxy reports should be treated as subjective perspectives that should all be taken into account whenever it is feasible. Children had the highest agreement with parents with mental illness school environment followed by the child's physical and mental health. Their ratings deviated most on social support and peer relationship, as do the child-parent ratings in the general population (Ravens-Sieberer, 2006). The results are in line with other research that found higher rater concordance for observable behaviors and emotions, as well as for school-related quality of life for which parents can rely on external sources such as teachers' reports or grades (Ravens-Sieberer et al., 2007; Robitail et al., 2006a). Although parents may notice how often children meet their friends, the quality of friendships and children's perceived social support are difficult for parents to assess, especially during adolescence (Chang, Yeh, & Cancer, 2005; Eiser & Varni, 2013). The HRQoL reports of children resembled their partners' ratings most on physical and mental health and least with regard to autonomy and parents, which was the only non-significant subscale. Hence, partners and children had different opinions regarding the quality of child-parent relationship, financial resources and the child's/adolescent's perceived level of autonomy. It is again conceivable that parents with mental illness were in closer contact with the children than their partners. Future research may add measures of the quantity and quality of child-parent interaction and communication to facilitate the interpretation of differences in rating perspectives.

The most influential factors associated with higher child-parent (dis)agreement regarding child HRQoL from the parents with mental illness' perspectives were the children's mental health and gender. Rater concordance was higher when children were male and had emotional and behavioral difficulties. From the partners' point of view, higher child-parent agreement was achieved when children were male and family functioning was high. From both parents' perspectives, the significant factors explained approximately a fifth of the variance in child HRQoL, suggesting that there may be other relevant factors that are associated with child-parent (dis)agreement. The impact of children's mental health on child-parent (dis)agreement has been observed in multiple studies and literature reviews (Dey, Landolt, Mohler-Kuo, et al., 2013; Eiser & Varni, 2013; Upton et al., 2008). It has been suggested that rater concordance between children and parents is higher when children suffer from mental health symptoms and that the parent's perspective can provide additional valuable information on HRQoL of these situations (Rajmil et al., 2013). Previous research on gender effects revealed mixed results. There is support for the present finding that boys showed higher agreement with their parents (Jokovic et al., 2003; Penney & Skilling, 2012), however another study reported the opposite (Robitail et al., 2006b), and yet others did not find any associations between the children's gender and child-parent agreement (Eiser & Morse, 2001). Studies that have examined the quality and quantity of child-parent interactions contradict the result of the present study which shows that from partners' view family dysfunction was associated with higher child-parent agreement (De Los Reyes & Kazdin, 2005; Grills et al., 2002; Jensen et al., 1988; Kolko et al., 1993; Treutler & Epkins, 2003).

The child's age, parental psychopathology and parental HRQoL did neither contribute to child-parent (dis)agreement from the parents' nor the children's' perspective. Inconsistent results have been reported for the effect of age on child-parent agreement (Annett et al., 2003; Kiss et al., 2009; Rajmil et al., 2013; Robitail et al., 2006a). However, irrespective of the significance of such age effects findings from previous research imply that concordance increases as children get older (Kiss et al., 2009; Robitail et al., 2006a) which contradicts the direction of age effects in this sample. In contrast to age effect, there is a relatively large scientific agreement that the parental psychopathology (Cremeens, Eiser, Blades, et al., 2006; Janicke et al., 2007; Kobayashi et al., 2011; Vance, Jenney, Eiser, & Morse,

2001) and parents' HRQoL (Berman et al., 2016b) affect their perceptions of child HRQoL. The analyses of child-parent agreement on HRQoL assessed with the KIDSCREEN-27 emphasize that each rating perspective should be treated as providing valuable and unique information and whenever possible clinicians and researchers should take multiple perspectives into account. Not least because different raters may experience the same situation differently and because raters may vary in their definitions of quality of life. This is especially applicable to settings in which parents' proxy reports may be affected by psychopathology, worries or the burden of caregiving (Eiser & Morse, 2001). The results of the present study can help clinicians to anticipate child-parent discordance on child HRQoL measures and take probable rater biases into account.

6.3. HRQoL of Partners of Parents with Mental Illness

The aim of the third research objective was to first compare the HRQoL of partners of parents with mental illness with data drawn from the general population, second to examine the impact of various risk and proactive factors on the partners' HRQoL. Partners self-reported significantly lower global HRQoL than the reference population on the EQ-5D-3L index but in contrast to the parents with mental illness not on the EQ-5D-3L VAS although the latter was lower than in the general population (Janssen et al., 2019). Compared to the reference population, a significantly higher proportion of partners reported problems with usual activities, pain/discomfort, and anxiety/depression, but no significant group differences were identified for mobility and self-care for which the proportion of people reporting any problems was even smaller in this sample. Significantly associated with the higher overall HRQoL were a good physical and mental condition, high levels of social support and a male gender. Those factors explained about half of the variance in the outcome. Adaptive coping and child mental health did not contribute to the overall HRQoL models. Satisfaction with mobility was more likely to be reported when partners were physically and mentally healthy, had social support, and used more maladaptive than adaptive coping strategies. No inferences could be made regarding self-care as only 5% of the partners reported problems regarding this HRQoL domain. Satisfaction with usual activities was significantly related to a good physical and mental health. No problems with pain and discomfort were significantly related to physical health, social support, a rare use of maladaptive coping strategies and a male gender. No problems with anxiety and depression were significantly associated with physical health and social support. The included factors explained 15-35% of the variance of domain-specific HRQoL. Family functioning, child psychopathology, and partners' age did not contribute to any of the domain-specific final HRQoL models.

In line with other research (Hsiao et al., 2020; Vadher et al., 2020; Walton-Moss, Gerson, & Rose, 2005; Zauszniewski et al., 2009) the results indicate that the overall HRQoL of partners of parents with parents with mental illness is likely to be reduced. Diminished quality of life in partners of people with mental illness have been attributed to high physical, psychological, social, and financial burdens as well as inadequate support from health professionals (Freed et al., 2015; Hsiao et al., 2020; Settineri et al., 2014; Siegenthaler, Munder, & Egger, 2012; Wiegand-Grefe, 2012). The insignificance of the EQ-5D-3L VAS may stem from the age standardization that was conducted. While partners were on average 40 years old, the reference population included people aged 75 years and older. It has been shown that HRQoL decreases with age and that the age-effect is more pronounced in the EQ-5D-3L VAS than in the EQ-5D-3L index (Janssen et al., 2019). Moreover, in the context of this study it was not assessed whether partners were the current intimate partners of the patient and whether they shared the same household. Thus, it may be that a proportion of partners did not have daily contact with the patient, which may explain why the HRQoL of partners was not significantly reduced on the EQ-5D-3L VAS. It has been shown that the quality of life of a person is more affected by the quality of life of another when family members had a close relationship (Caqueo-Urízar et al., 2017; Rudnick, 2004). Nevertheless, compared to the general population a significantly higher proportion of partners had problems with usual activities such as professional work, house chores, family and leisure activities, pain/discomfort, and anxiety/depression. Those observations are in accordance with other studies showing that psychopathology of parents can disrupt the family routine, interactions and leisure activities, and may be accompanied by social isolation and occupational restrictions (Poon et al., 2017; Vikas et al., 2011; Zauszniewski et al., 2009). About one third of the partner sample reported physical impairments ranging from headaches to serious physical illnesses that may explain the HRQoL impairment in the domain pain/discomfort. Research involving more than 300 relatives of hospitalized mental health patients indicate that relatives have elevated pain levels (Fleischmann & Klupp, 2004). This may especially apply to partners with high levels of neuroticism (Möller-Leimkühler & Mädger, 2011). A part of the elevated levels of pain and discomfort in partners of mentally ill patients may express somatic complaints. A descriptive study found moderately high to high levels of psychosomatic problems in 120 caregivers of patients with mental illness. No significant differences were identified among major mental illnesses including schizophrenia, mood disorders and alcohol dependence (Sumi, Punnoose, & Cyriac, 2017). A higher proportion of anxiety- and depression-related problems in this sample is in accordance with other studies that consistently shown that the prevalence of mental health symptoms in relatives including intimate partners is up to two times higher than in the general population particularly when relatives have a high caregiver burden, face adverse psychosocial circumstances, and when the patients’ mental health symptoms are severe (Heru et al., 2005; Magaña et al., 2007; Poon et al., 2017; Zauszniewski et al., 2009). Partners in this sample reported even fewer problems with mobility and self-care than their peers from the general population, which may also be attributable to the young age of the sample. Higher overall HRQoL of partners was significantly associated with the partners’ physical and mental health along with high levels of social support and a male gender. Results are consistent with other studies that reported better HRQoL among physically and mentally healthy individuals (Fontaine & Barofsky, 2001; Sobocki et al., 2007; Strine et al., 2008; Vadher et al., 2020) as well as for caregivers that experience high levels of social support (Derajew et al., 2017; Hsiao et al., 2020; Leng et al., 2019). Because about one third of families affected by parental mental illness receive inadequate social support and caregivers show decreased initiative to seek social support it is important to assist partners of mentally ill patients with social support programs in order to enhance their quality of life (Leng et al., 2019; Wiegand-Grefe et al., 2012). Worse quality of life reports and a higher caregiver burden in women compared to men are common findings in the caregiver literature (Opoku-Boateng et al., 2017; Vadher et al., 2020; Zendjidjian et al., 2012) and in the general population (Janssen et al., 2019). Lower HRQoL of women compared to men may be attributed to more sociodemographic disadvantages such as lower average income and a higher proportion of singles compared to men (Vadher et al., 2020). In contrast to the prior-stated hypotheses and past research, adaptive coping and child psychopathology did not contribute to overall HRQoL (Grover & Pradyumna, 2015; Möller-Leimkühler & Mädger, 2011; Vollrath et al., 2003). The latter may have occured because the EQ-5D is not sensitive enough to themes like children’s well-being that bother the families of mental health patients (Brazier et al., 2014). Half of the variance in overall HRQoL and more than two third of the domain-specific HRQoL variance remained unexplained indicating that there may be unknown predictors exerting an influence on HRQoL.

Consistent with other studies physical health was associated with mobility (Mollaoğlu et al., 2010). It is unclear however, how the association between mental health symptoms and mobility could be interpreted. It may be that partners with mental health symptoms showed social withdrawal tendencies and thus spend more time at home than walking around. Social withdrawal tendencies are common among individuals with mental health conditions, particularly among those with schizophrenia and mood disorders (Rios & Perlman, 2018). Social contacts may take over partners’ caring responsibilities, which may support partners in their mobility. In contrast to the hypotheses and previous research, adaptive coping was associated with mobility-related problems while maladaptive coping had the opposite effect (Grover & Pradyumna, 2015; Mohr et al., 2014). This may probably relate to the questionnaire’s vague definitions of coping strategies, that was discussed earlier. Similar to mentally ill patients, partners were satisfied with their usual activities (e.g., work, family, recreational activities) when they were physically and mentally healthy. This is consistent with other studies that showed that physical and mental illness interferes with activities of daily living (Barile et al., 2012; den Ouden et al., 2013; Frost et al., 2013; I. Goetz et al., 2007).

Partners felt painless and comfortable when they were physically healthy, had social support, rarely used maladaptive coping and when they were male. This is in line with other studies that have observed more pain in physical illnesses (Mirmosayyeb et al., 2020; Van Den Beuken-Van et al., 2016), reduced HRQoL perceptions among women (Janssen et al., 2019; Opoku-Boateng et al., 2017; Vadher et al., 2020) and that have reported about the benefits of social support (Che, Cash, Ng, Fitzgerald, & Fitzgibbon, 2018) and coping on physical health and HRQoL (Grover & Pradyumna, 2015; Mohr et al., 2014).

Partners' satisfaction with the HRQoL domain anxiety and depression was significantly associated with physical health and social support. Support for the association anxiety/depression with physical health comes from research that has reported an elevated risk of mental health symptoms in individuals with physical impairments especially in people with physical long-term conditions (Hudson & Moss-Morris, 2019). Furthermore, studies have detected a higher prevalence of physical illness (e.g., coronary heart disease) among people with mental disorders that account for the shorter life expectancy of patients with severe mental illness compared to general population (De Hert, Detraux, & Vancampfort, 2018; Nielsen, Banner, & Jensen, 2020). Social support promotes mental and physical health and quality of life, and it is associated with a range of health-promoting behaviors such as positive role functioning, psychosocial adjustment, adaptive coping and self-actualization (Ay-Woan et al., 2006; Saunders, 2003; Zeng et al., 2017). It is unclear, why mental health did not contribute to the HRQoL domain anxiety/depression although the variables are conceptually-related. Nevertheless, according with other studies mental health was significantly related to overall HRQoL of partners (Sobocki et al., 2007; Vadher et al., 2020). The factors family functioning, child mental health and the partners' age did not have significant effects on any of the domain-specific final HRQoL models, which contradicts previous research (Hsiao et al., 2020; Rüsch et al., 2019; Souza et al., 2017; Vasilopoulou & Nisbet, 2016; Yazici et al., 2016; Zeng et al., 2020).

6.4. The Link Between Family Members' HRQoL

The fourth research objective aimed to compare family members' overall HRQoL with each other. The cross-correlational analysis showed that the more the children were satisfied with their overall HRQoL the higher the parents with mental illness and the partners viewed their own HRQoL. The link between parental HRQoL ratings was less clear. Higher HRQoL of one parent was significantly associated with lower HRQoL of the other parent when HRQoL was assessed with the EQ-5D VAS. However, when HRQoL was assessed with the EQ-5D index, parents' HRQoL appeared to be non-significantly positively related. Although family members had similar perceptions of children's current life satisfaction, correlations of parental and child HRQoL were only significant when HRQoL values were assessed from the same rater.

Yet only one study has directly investigated the relationship between family members' HRQoL when one family member had a mental illness (Caqueo-Urízar et al., 2017). Because the study by Caqueo-Urízar and colleagues (2017) involved patients with schizophrenia and their adult family caregivers, no conclusions can be made for the child-parent correlations. However, research on physical illness supports the present findings. For instance, significant positive correlations between children's and parents' quality of life were found in families of children with congenital heart disease (Goldbeck & Melches, 2005) and in studies on pediatric asthma (Price, Bratton, & Klinnert, 2002; Vila et al., 2003) although the magnitude of the effect was slightly higher compared to the present sample (Goldbeck & Melches, 2005). Correlations between parental and child HRQoL may increase, when HRQoL is assessed with questionnaires that focus on similar aspects of HRQoL. In this study, parental HRQoL was assessed with the EQ-5D-3L and child HRQoL with the KIDSCREEN-27. While the items of the EQ-5D-3L are primarily related to physical health, the items of the KIDSCREEN are mainly associated with psychological aspects of quality of life. No causal inferences could be made about the direction of the positive intercorrelations between parental and child HRQoL. The positive association can indicate either an impact of parental HRQoL on the children's HRQoL, an impact of children's HRQoL on parental HRQoL, or reciprocal effects through child-parent interactions.

The direction and magnitude of the correlations between parental HRQoL ratings was less conclusive and the analyzes yielded contradictory results depending on the outcome measure. However, this inconclusiveness and contradiction has been observed in other studies, too. Most of the mental health studies did not report the proportion of intimate partners among caregivers of the patients with mental illness although the descriptive statistics indicate that at least part of the caregiver sample consistent of intimate partners. Caqueo-Urízar and colleagues (2017) found no significant correlations between caregivers' quality of life and patients with schizophrenia except for the quality of life dimension family relationships. Other studies indicated a positive correlation between the patients' quality of life and the burden of relatives including partners (Hjärthag et al., 2008; Parabiaghi et al., 2007; Perlick et al., 2006; Rhee & Rosenheck, 2019). Research on physical impairments found significant correlations between the patient's and the partner's level of distress but the studies reported opposing directions (Baider & Bengel, 2001; Bergelt et al., 2008).

In accordance with ICC analyses of the second research objective and with normative data (Ravens-Sieberer, 2006), parents and children had similar perceptions of the children's current HRQoL. Higher correlations among values assessed from the same rating perspective are, for example, in line with a study involving physically ill children and their families (Goldbeck & Melches, 2005).

To sum up, the correlational analyses indicate that there is a link between family members' HRQoL. However, the correlational nature of the analysis and the cross-sectional design of the study did not allow to make causal inferences. The analyses of the longitudinal data that was gathered in the context of the overall multicenter randomized controlled CHIMPS project may shed light on the causal relationships between family members HRQoL (Wiegand-Grefe et al., 2021).

6.5. Limitations

This study of the present research objectives had several limitations. First of all, data came from baseline assessments of the German randomized controlled multicenter study 'CHIMPS'. Hence, the predictive capacity of HRQoL determinants that were investigated in this research is limited because all variables were simultaneously measured. To make causal inference about HRQoL predictors and to examine the temporal relationship between predictors and the outcome, the analyses should be repeated when the longitudinal data are available.

Second, future research should take additional predictors of HRQoL into account that could not considered in this dissertation. For instance, no information was available on socioeconomic status although research has shown that financial problems can reduce individual HRQoL (Hsiao et al., 2020; Leng et al., 2019). Future studies may further include the children's coping behavior as a predictor for child HRQoL. The relevance of the children's coping has been demonstrated by previous interventions developed for COPMI (Reupert & Maybery, 2010; Reupert & Maybery, 2009). Furthermore, future studies should use an objective measure of physical health (e.g., questionnaire, medical records) to better understand why all family members' physical HRQoL was impaired. In this context, physical health was assessed with the individual item 'Are you currently suffering from physical illness?' with the answer option 'I am currently healthy' vs. 'I currently suffer from … (please explain)'. A systematic differentiation between the symptom severity or the type of medical impairments such as headaches, a broken leg, cancer or somatic symptoms originating from psychopathology was not possible. Similarly, no data were available about the characteristics of the parental psychopathology such as symptom severity, chronicity, prognosis, care degree, and duration of mental illness. To compensate for the limited information, psychopathology was assessed with the Brief Symptom Inventory (BSI). The advantage of the BSI was also the inclusion of items on somatic complaints.

The psychiatric diagnoses of patients who participated in the CHIMPS project were made by the clinicians in charge. However, a standardized measure would be more informative. For instance, future research may include the structured clinical interview for DSM-5 (SCID-5-RV, First, Williams, Karg, & Spitzer, 2015) to systematically document the characteristics of mental illness with a standardized instrument like subtypes, severity levels and course specifiers, as well as to ensure that the clinical inclusion criteria (presence of a formal mental diagnosis) are met.

Another limitation relates to the recruitment strategy of the CHIMPS project. The results may be slightly biased because the family intervention of the project may have attracted a higher proportion of families with relatively intact family functioning. Moreover, most patients with mental illness were female, which may have reduced the sample's average quality of life as women tend report lower quality of life in all EQ-5D dimensions across countries (Janssen et al., 2019).

Another limitation refers to the assessment of parental HRQoL. Parents' HRQoL was assessed with the EQ-5D that focuses primarily on physical quality of life components like the ability to care for oneself and to walk. However, the HRQoL of parents with mental illness may particularly be determined by mental (e.g., family functioning, social network and occupational functioning) rather than physical quality of life components. Future researchers need to weigh up the benefits of the EQ-5D (timesaving, easy to administer and to integrate in clinical practice) against the drawbacks, in particular the limited coverage of themes that bother families affected with mental illness. Furthermore, the utility of the EQ-5D in HRQoL research involving mentally ill patients and healthy respondents may be explored in more detail by means of psychometric analyses.

6.6. Implications

The results of this dissertation indicate that HRQoL is reduced in families affected by parental mental illness especially with regard to mental and physical aspects of HRQoL. Parents were in addition dissatisfied with occupational, familial and social activities. The results emphasize that clinicians, policymakers and society should pay more attention to the detrimental effects of mental illness on families and to improve access to effective interventions in order to promote their HRQoL. Interventions for affected families require empathy for the families' individual needs, interagency collaboration (e.g. between child and adult services), standard intake practice, professional knowledge and skills of health care providers, family-friendly environments as well as evidence-based interventions that may be delivered in an individual or group setting (Krumm, Becker, & Wiegand-Grefe, 2013). The clinical and cost effectiveness of such evidence-based interventions may be assessed with HRQoL measures (Coker et al., 2011; Kang et al., 2020; Kilian et al., 2017; Waldmann et al., 2021; Wiegand-Grefe et al., 2021).

The results further underscore the importance of the timely clinical identification of family members affected by parental mental illness that are at-risk to develop any mental or physical illness. HRQoL may be helpful measure in identifying those individuals, and thus should be included in standardized clinical assessments (Hagen et al., 2019). The early identification and treatment of family members who display poor HRQoL can prevent an adverse psychological development and high treatment costs in the future (Kilian et al., 2017; Waldmann et al., 2021; Wiegand-Grefe et al., 2021)

The findings of this dissertation are consistent with the recovery philosophy of expanding treatment options for affected families beyond the pure alleviation of parental mental health symptoms, which may not reduce difficulties with daily activities, financial burdens, stigmatization or loneliness (Narvaez et al., 2008; Perlick et al., 2006). The results of the regression analyses suggest that interventions for parents with mental illness and their families should primarily focus on the improvement of individual mental and physical health, and secondly promote family functioning, social support, and adaptive coping in their patients. Psychotherapy, family interventions and peer support groups are most likely to meet the needs of affected families and enhance family members' HRQoL (Castelein et al., 2008; Wiegand-Grefe et al., 2016; Wiegand-Grefe et al., 2015; Wiegand-Grefe et al., 2013; Wiegand-Grefe, Susanne Halverscheid, et al., 2011; Wiegand-Grefe et al., 2012). For example, the predecessor CHIMPS study compared families who participated in the manualized family intervention CHIMPS with families of a waiting-list control group. The pre-post pilot trial showed that the family intervention successfully improved i.a. the children's social support, mental health, quality of life, family relationships and parents' coping strategies (Wiegand-Grefe et al., 2016; Wiegand-Grefe et al., 2015; Wiegand-Grefe et al., 2013; Wiegand-Grefe, Susanne Halverscheid, et al., 2011; Wiegand-Grefe et al., 2012). Families may also benefit from interdisciplinary clinical exchange between psychologists and physicians because mental and physical HRQoL were the most impaired aspects reported by parents with mental illness, their partners and children. Especially parents with mental illness may benefit from the assessment and treatment of physical symptoms (including somatic complaints) like chronic pain or migraine as an integral part of mental health treatment (Stubbs et al., 2015).

The insignificance of some parental HRQoL determinants (e.g., child psychopathology, family functioning) may at least partly be attributed the EQ-5D's limited coverage of themes that bother people with mental illness and their partners (Brazier et al., 2014). Clinicians and researchers should carefully weigh up the pros (e.g., timesaving, cognitive undemanding) and cons (e.g., limited coverage of HRQoL determinants) of the EQ-5D in mental health settings.

This is the first study that has systematically examined the magnitude, direction and prediction of child-parent agreement regarding the HRQoL of COPMI with intraclass correlation coefficients and regression analyses. All in all, children and parents showed fair congruence for most but not all global and specific aspects of child HRQoL. Disagreement on some aspects of child HRQoL (e.g., autonomy and parents) emphasize the need to obtain both perspectives whenever possible. Children should be provided the opportunity to report their own perspective on HRQoL. This is particularly useful for HRQoL aspects that are less observable for proxy-raters, for example, the quality of peer relationships and mental health aspects. The mere reliance on parents' proxy-reports can be useful in situations, in which children feel unable to self-report e.g., due to illness, cognitive deficits or a young age. Parents' proxy-reports may also be obtained in addition to the children's reports when children are suspected to overreport high HRQoL to protect their parents or because they think it is socially desirable. Research should continue to examine child-parent agreement and to identify factors that are associated with disagreement such as family dysfunction. Studies like the present one can aid clinicians and researchers to evaluate the utility of a HRQoL instrument for a given sample and context (e.g., in dysfunctional families).

The results of the correlational analyses indicate that there is a link between family members' HRQoL, particularly between children and their parents. The longitudinal data of this multicenter randomized controlled CHIMPS project should be analyzed with regression analyses in order to make causal inferences about the link between family members HRQoL (Wiegand-Grefe et al., 2021).

7. Conclusion

The results show that HRQoL is significantly reduced in families affected by parental mental illness compared to the general population, especially in the patients themselves. Parents with mental illness, their children and partners were least satisfied with mental and physical aspects of HRQoL with parents reporting additional impairments regarding their occupational, familial and social activities. In accordance, higher overall HRQoL of parents was primarily associated with physical and mental health. Moreover, from the parents with mental illness' perspectives, adaptive coping behavior exerted a positive influence on their HRQoL while partners appreciated high levels of social support and reported higher HRQoL when they were male. Both parents reported significantly higher HRQoL for their children when the children were mentally healthy, received social support and had a young age. In addition, parental mental health symptoms and coping affected child HRQoL from the parents with mental illness' and the partners' perspective respectively. The children themselves reported higher HRQoL when they were mentally healthy, had social support and lived in high functional families. The HRQoL of family members was weakly to moderately correlated. The strongest relationship was observed between children and parents when HRQoL was assessed from the same rating perspective.

Clinicians and policymakers should improve the access to effective interventions and identify family members at risk for mental health symptoms as early as possible in order to avert detrimental psychological developments and high treatment costs, and most important to improve their HRQoL. The improvement of HRQoL should become a major treatment goal because the HRQoL concept covers many factors that are central to the individual well-being (e.g., health, social connectedness, family functioning). Interventions that primarily target mental and physical health and secondly promote family functioning, social support, and adaptive coping in parents with mental illness are most likely to improve the families' HRQoL.

The predominant fair congruence between children and parents regarding child HRQoL indicates that the parental proxy-version of the KIDSCREEN-27/10 is a useful addition to the child self-reports and could be used in replacement when the children are unable to self-report. Child self-reports are particularly useful regarding unobservable aspects of HRQoL (e.g., quality of peer relationships). Children and parents showed higher agreement regarding child HRQoL when children were male, had mental health symptoms and lived in high functional families. The results can help clinicians and researchers to anticipate situations in which the inquiry of the children's' and parents' perspectives are advantageous.

Clinicians and researchers should carefully weigh up the benefits and drawbacks of the EQ-5D when assessing HRQoL of families affected by mental illness. Although it is timesaving and can easily integrated in clinical practice, it provides a limited coverage of themes that determine the HRQoL of parents with mental illness and their families.

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Appendix

Internal Consistencies

Table 24. Internal consistencies (Cronbach’s α) of questionnaires by research objective

		Research Objective			
		1	**2**	**3**	**4**
Measure	**N Items**	α	α	α	
KIDSCREEN-27 Subscales					
Child self-report					
Physical well-being	5		.65		.65
Mental health	7		.90		.90
Autonomy and parents	7		.81		.81
Social support and peers	4		.84		.84
School environment	4		.83		.83
Mentally ill parent proxy-report					
Physical well-being	5		.73		.73
Mental health	7		.89		.89
Autonomy and parents	7		.80		.80
Social support and peers	4		.91		.91
School environment	4		.89		.89
Partner proxy-report					
Physical well-being	5		.69		.69
Mental health	7		.90		.90
Autonomy and parents	7		.80		.80
Social support and peers	4		.89		.89
School environment	4		.86		.86
KIDSCREEN-10 Index					
Child self-report	10		.83		.83
Mentally ill parent proxy-report	10		.82		.82
Partner proxy-report	10		.80		.80
BSI Global Severity Index					
Mentally ill parent self-report	53	.96	.97		
Partner self-report	53		.97	.96	
CBCL-4-18 Total Problems					
Mentally ill parent proxy-report	113	.94	.95		
Partner proxy-report	113		.95	.95	
YSR Total Problems	112		.92		
FQCI					
Mentally ill parent self-report					
Depressed processing style	5	.63	.65		
Active problem-oriented coping	5	.71	.70		
Distraction and self-growth	5	.65	.65		
Religiosity and quest for meaning	5	.52	.49		
Trivialization and wishful thinking	3	.69	.72		
Adaptive Coping	10	.76			
Maladaptive Coping	13	.67			

Partner self-report				
Depressed processing style	5			.65
Active problem-oriented coping	5			.69
Distraction and self-growth	5			.65
Religiosity and quest for meaning	5			.49
Trivialization and wishful thinking	3			.72
Adaptive Coping	10			.79
Maladaptive Coping	13			.76
FB-A				
Mentally ill parent self-report	28	.94	.93	
Child self-report	28		.92	
Partner self-report	28		.91	.91
OSSS-3				
Mentally ill parent self-report	3	.31		
Mentally ill parent proxy-report	3		.69	
Child self-report	3		.48	
Partner self-report	3			.66
Partner proxy-report	3		.63	

Note. n = 208 parents and *n* = 197 children and adolescents aged 4-18 (research objective 1), *n* = 134 parents and *n* = 198 children and adolescents aged 8-18 (research objective 2), *n* = 195 parents and *n* = 290 children and adolescents aged 8-18 (research objective 3).

Sample Characteristics by Research Objective

First Research Objective

Table 25 and *Table 26* present the characteristics of *n* = 208 parents with mental illness and their *n* = 197 children and adolescents aged 4 to 18 years respectively. Parents were on average 40 years old. Three out of four parents were female. Half of the sample was married. The majority had 10-13 years of school education. Participants were primarily diagnosed according to the ICD-10 with mood (affective) disorders (F30-F39, for example major depressive disorder), followed by disorders of adult personality and behavior (F60-F69, for example paranoid personality disorder), neurotic, stress-related and somatoform disorders (F40-F48, for example phobias, obsessive-compulsive disorder). Underrepresented primary diagnoses were schizophrenia, schizotypal, and delusional disorders (F20–F29, for example delusional disorder), mental and behavioral disorders due to psychoactive substance use (F10–F19, for example alcohol dependence) and behavioral and emotional disorders with onset usually occurring in childhood and adolescence (F90–F98, for example attention deficit hyperactivity disorder). Approximately half of the parents had psychiatric comorbidities. The subjective psychiatric symptom burden was clinically remarkable in most cases (BSI raw score ≥ 0.62). Participants predominantly used active problem-oriented coping to deal with distress followed by a depressed processing style. Half of the sample self-reported physical impairments. Parents scored on average *M* = 36.76 (*SD* = 15.33) on family functioning assessed with the FB-A, and *M* = 9.41 (*SD* = 1.63) on social support assessed with the OSSS-3. They were moderately satisfied with their current HRQoL. The majority expressed problems with anxiety/depression, pain/discomfort and usual activities. Only a quarter of parents reported problems with self-care and mobility. Parents had on average two children with a mean age of *M* = 12.17 (*SD* = 3.09) years. They proxy-reported for their children on average a total CBCL 4-18 score of *M* = 38.02 (*SD* = 25.47).

Table 25. Characteristics of parents with mental illness (first research objective)

Characteristics	*n* (%)	*M* (*SD*)	Possible Score Range
Parents with mental illness			
Sociodemographic data [1,a]			
Age (in years)[1]		40.04 (7.15)	
Female	157 (75.5%)		
Married	112 (54.6%)		
School education			
11-13 years education	64 (32.0%)		
10 years education	90 (45.0%)		
9 years education	42 (21.0%)		
No secondary education	4 (2.0%)		
Mental health			
Psychiatric diagnosis (ICD-10)[2, b]			
F10 – F19	3 (1.4%)		
F20 – F29	10 (4.8%)		
F30 - F39	120 (57.7%)		
F40 - F48	25 (12.0%)		
F60 - F69	49 (23.6%)		
F90 – F98	1 (0.5%)		
Comorbidity (ICD-10)[2,b]	84 (40.4%)		
Psychopathology (BSI, GSI)[1]		1.35 (0.69)	0-4
Parental Coping (FQCI)[1]			
Adaptive coping		3.02 (0.60)	1-5
Maladaptive coping		4.18 (0.85)	1-5
Physical impairments[1]	102 (50.5%)		
Family functioning (FB-A, total score)[1]		36.76 15.33)	0-120
Social support (OSSS-3, total score)[1]		9.41 (1.63)	3-15
HRQoL (EQ-5D-3L)[1]			
Mobility (any problems)	48 (23.1%)		1-2
Self-care (any problems)	55 (26.4%)		1-2
Usual activities (any problems)	135 (64.9%)		1-2
Pain/ discomfort (any problems)	143 (68.8%)		1-2
Anxiety/depression (any problems)	183 (88.0%)		1-2
VAS		54.22 (19.67)	0-100
Index		0.56 (0.22)	-0.21-1

Note. *n* = 208 parents with mental illness. Questionnaire-related scores were based on raw data; for details, see text (Methods). [1] based on parent self- and proxy reports. [2] based on proxy-ratings by clinicians. [a] ad-hoc items [b] International Classification of Diseases (ICD-10) codes: mental and behavioral disorders due to psychoactive substance use (F10–F19), schizophrenia, schizotypal, and delusional disorders (F20–F29), mood (affective) disorders (F30–F39), neurotic, stress-related and somatoform disorders (F40–F48), disorders of adult personality and behavior (F60–F69), behavioral and emotional disorders with onset usually occurring in childhood and adolescence (F90–F98).

Table 26. Sample characteristics of the children (first research objective)

Characteristics	*n* (%)	*M* (*SD*)	Possible Score Range
Children			
Number of children[1,a]		1.91 (0.93)	
Age (in years)[1,a]		12.17 (3.09)	
Female[1,a]	109 (55.3%)		
Child psychopathology (CBCL 4-18)[1]			
Internalizing symptoms		13.48 (10.00)	0-62
Externalizing symptoms		11.35 (9.88)	0-66
Total problems		38.02 (25.47)	0-113

Note. *n* = 197 children and adolescents. Questionnaire-related scores were based on raw data; for details, see text (Methods). [1] based on mentally ill parent proxy reports. [a] ad-hoc items.

Second Research Objective

The sample characteristics of the 134 families that were included for this research objective are displayed in *Table 27* - *Table 29*. The n = 134 parents with mental illness (n = 102 mothers, n = 32 fathers) had a mean age of *M* = 41.59 (*SD* = 6.77). About half of them was married. Most parents with mental illness had 10 to 13 years of school education. The most prevalent primary psychiatric ICD-10 diagnoses were mood (affective) disorders (F30–F39), followed by disorders of adult personality and behavior (F60–F69), neurotic, stress-related and somatoform disorders (F40–F48) and other psychopathologies. Half of the parental sample had psychiatric comorbidities. The psychiatric symptom burden was remarkable for most parents (BSI raw score ≥ 0.62). To deal with psychopathology and its consequences the majority of parents used active problem-oriented coping, followed by a depressed processing style. The current health satisfaction of parents with mental illness was moderate. Children and adolescents were on average 12 years old. Both sexes were equally represented. The majority had sibling and shared the household with their parents. Parents with mental illness proxy-reported for social support a mean value of *M* = 10.25 (*SD* = 2.40) measured with the OSSS-3. Child HRQoL was assessed from all rating perspectives with similar assessments of overall quality of life that indicate moderate life satisfaction. Partners had a mean age of 43 years. About two third of the sample was male. Most of them were married and had 10-13 years of school education. They reported no remarkable psychiatric symptom burden (BSI raw score < 0.62). The partners were relatively satisfied with their overall HRQoL.

Table 27. Characteristics of parents with mental illness (second research objective)

Characteristics	*n* (%)	*M* (*SD*)	Possible Score Range
Parents with mental illness			
Sociodemographic data[1,a]			
Age (in years)		41.59 (6.77)	
Female	102 (76.1%)		
Number of children		2.14 (0.94)	
Married	75 (56.4%)		
School education			
11-13 years education	39 (30.5%)		
10 years education	60 (46.9%)		
9 years education	26 (20.3%)		
No secondary education	3 (2.3%)		
Mental health			
Psychiatric diagnosis (ICD-10) [2,b]			
F10 – F19	2 (1.5%)		
F20 – F29	4 (3.0%)		
F30 - F39	75 (56.0%)		
F40 - F48	15 (11.2%)		
F60 - F69	37 (27.6%)		
F90 – F98	1 (0.7%)		
Comorbidity (ICD-10) [2,b]	56 (41.8%)		
Symptom burden (BSI, GSI)[1]	109 (83.2%)	1.36 (0.72)	0-4
Parental Coping (FQCI)[1]			
Depressed processing style		15.43 (3.79)	1-5
Active problem-oriented coping		16.12 (3.78)	1-5
Distraction and self-growth		13.85 (3.31)	1-5
Religiosity and quest for meaning		13.11 (3.38)	1-5
Trivialization and wishful thinking		7.87 (3.13)	1-5
Family functioning (FB-A) [1]		38.63 (14.70)	0-120
Social support (OSSS-3) [1]		10.25 (2.40)	3-15
HRQoL (EQ-5D-3L, index)[1]		0.57 (0.22)	-0.21-1.00

Note. *n* = 134 parents with mental illness. Questionnaire-related scores were based on raw data; for details, see text (Measures). [1] based on parent self-reports. [2] based on proxy-ratings by clinicians. [a] ad-hoc items [b] International Classification of Diseases (ICD-10) codes: mental and behavioral disorders due to psychoactive substance use (F10–F19), schizophrenia, schizotypal, and delusional disorders (F20–F29), mood (affective) disorders (F30–F39), neurotic, stress-related and somatoform disorders (F40–F48), disorders of adult personality and behavior (F60–F69), behavioral and emotional disorders with onset usually occurring in childhood and adolescence (F90–F98).

Table 28. Characteristics of children and adolescents aged 8-18 years (second research objective)

Characteristics	*n* (%)	*M* (*SD*)	Possible

			Score Range
Children			
Sociodemographic data[a]			
Age (in years)[2]		12.19 (3.09)	
Female[2]	110 (56.1%)		
Shared household with mentally ill parent[2]	165 (86.4%)		
(Step) siblings[1]	164 (82.4%)		
HRQoL (child self-report) [1]			
KIDSCREEN-10 index		37.84 (6.71)	10-50
KIDSCREEN-27, physical well-being		15.04 (3.66)	5-25
KIDSCREEN-27, mental health		26.45 (5.91)	7-35
KIDSCREEN-27, autonomy and parents		27.49 (5.32)	7-35
KIDSCREEN-27, social support and peers		15.81 (3.62)	4-20
KIDSCREEN-27, school environment		14.72 (3.48)	4-20
HRQoL (mentally ill parent proxy-report)[2]			
KIDSCREEN-10 index		36.60 (5.70)	10-50
KIDSCREEN-27, physical well-being		15.64 (3.53)	5-25
KIDSCREEN-27, mental health		25.39 (4.68)	7-35
KIDSCREEN-27, autonomy and parents		26.72 (4.41)	7-35
KIDSCREEN-27, social support and peers		14.00 (3.43)	4-20
KIDSCREEN-27, school environment		14.32 (3.42)	4-20
HRQoL (partner proxy-report)[3]			
KIDSCREEN-10 index		37.74 (5.55)	10-50
KIDSCREEN-27, physical well-being		15.68 (3.40)	5-25
KIDSCREEN-27, mental health		26.37 (5.05)	7-35
KIDSCREEN-27, autonomy and parents		27.83 (4.12)	7-35
KIDSCREEN-27, social support and peers		14.10 (3.49)	4-20
KIDSCREEN-27, school environment		14.68 (3.31)	4-20
Mental health (YSR/ CBCL 4-18, total problems)			
Child self-report[1]		67.03 (21.12)	0-112
Mentally ill parent proxy-report [2]		37.90 (25.72)	0-113
Partner proxy-report[3]		26.47 (21.70)	0-113
Family functioning (FB-A)[1]		31.34 (14.84)	0-120
Social support (OSSS-3)[1]		10.79 (2.33)	3-15

Note. *n* = 198 children (*n* = 136 child self-reports, *n* = 189 mentally ill parent proxy-reports, *n* = 141 partner proxy-reports). Questionnaire-related scores were based on raw data; for details, see text (Measures). [1] based on child self-reports. [2] based on the mentally ill parent' proxy-reports. [3] based on the partner/caregiver's proxy-report. [a] ad-hoc items.

Table 29. Characteristics of partners (second research objective)

Characteristics	*n* (%)	*M* (*SD*)	Possible Score Range
Partners			
Sociodemographic data^{1,a}			
Age (in years)		42.35 (6.66)	
Female	36 (38.7%)		
Number of children		2.23 (1.00)	
Married	108 (77.1%)		
School education			
11-13 years education	35 (38.5%)		
10 years education	33 (36.3%)		
9 years education	22 (24.2%)		
No secondary education	1 (1.1%)		
Mental health^{1}			
Psychopathology (BSI, GSI)		0.52 (0.54)	0-4
Family functioning (FB-A)^{1}		30.48 (13.38)	0-120
Social support (OSSS-3)^{1}		10.87 (2.18)	3-15
HRQoL (EQ-5D-3L, index)^{1}		0.81 (0.15)	-0.21-1.00

Note. *n* = 94 partners. Questionnaire-related scores were based on raw data; for details, see text (Measures). ^{1} based on parent self-reports. ^{a} ad-hoc items.

Third Research Objective

Table 30 and *Table 31* display the characteristics of *n* = 141 partners and *n* = 140 children and adolescents aged 4 to 18 years, respectively. Partners were on average 40.33 (*SD* = 6.98) years old. About one third of participants was female. Most of them were married. On average partners had two children. The majority of the parental sample hat 10-13 years of school education. Partners experienced on average no clinically remarkable psychiatric symptoms (BSI raw score < 0.62). Active problem-oriented coping was the most employed coping strategy followed by distraction and self-growth. One third of the parental sample self-reported physical complaints that were not further defined (e.g., headaches, cancer). Partners reported average scores of *M* = 30.34 (*SD* = 13.27) on family functioning and *M* = 9.69 (*SD* = 2.73) on social support. They were relatively satisfied with their current HRQoL. Self-care appeared to be least impaired HRQoL domain while pain/discomfort was the area where most problems were reported. The children that were considered for the third research objective were on average 12-13 years old. Most of them were the biological children of the partner. The other children were either adoptive or foster children. The parental sample proxy-reported a total CBCL-4-18 score (child psychopathology) with *M* = 33.87 (*SD* = 28.42).

Table 30. Characteristics of partners (third research objective)

Characteristics	*n* (%)	*M* (*SD*)	Possible Score Range
Partners[1]			
Sociodemographic data [a]			
Age (in years)		40.33 (6.98)	
Female	52 (36.9%)		
Married	103 (73.0%)		
Number of children		1.99 (0.94)	
School education			
11-13 years education	53 (39.0%)		
10 years education	51 (37.5%)		
9 years education	31 (22.8%)		
No secondary education	1 (0.7%)		
Mental health			
Psychopathology (BSI, GSI) [b]		0.51 (0.54)	0-4
Parental Coping (FQCI) [c]			
Depressed processing style		2.15 (0.74)	1-5
Active problem-oriented coping		3.28 (0.78)	1-5
Distraction and self-growth		2.90 (0.78)	1-5
Religiosity and quest for meaning		2.52 (0.80)	1-5
Trivialization and wishful thinking		1.89 (0.81)	1-5
Physical impairments [a]	49 (35.3%)		
Family functioning (FB-A, total score) [d]		30.34 (13.27)	0-120
Social support (OSSS-3, total score) [e]		9.69 (2.73)	3-15
HRQoL (EQ-5D-3L) [f]			
Mobility (any problems)	22 (15.6%)		1-2
Self-care (any problems)	4 (2.8%)		1-2
Usual activities (any problems)	29 (20.6%)		1-2
Pain/ discomfort (any problems)	71 (50.4%)		1-2
Anxiety/depression (any problems)	46 (32.6%)		1-2
VAS		74.76 (19.05)	0-100
Index		0.81 (0.16)	-0.21-1

Note. *n* = 141 partners. [1] based on self-reports of partners. Questionnaire-related scores were based on raw data; for details, see text (Methods). [a] ad-hoc items.

Table 31. Characteristics of children and adolescents aged 8-18 years (third research objective)

Characteristics	*n* (%)	*M* (*SD*)	Possible Score Range
Children[1]			
Age (in years)[a]		12.82 (3.22)	
Female[a]	52 (55.9%)		
Biological children of partner	112 (83.6%)		
Child psychopathology (CBCL 4-18, total score) [g]		33.87 (28.42)	0-113

Note. *n* = 140 children and adolescents. [1]based on proxy reports of partners. Questionnaire-related scores were based on raw data; for details, see text (Methods). [a] ad-hoc items.

Fourth Research Objective

Table 34 - *Table 36* display the characteristics of *n* = 208 parents with mental illness, *n* = 198 children and adolescents aged 8 to 18 years and *n* = 141 partners. Parents with mental illness were moderately satisfied with their current HRQoL. They reported mostly difficulties with anxiety/depression followed by pain/discomfort and usual activities. Moderate child HRQoL was indicated from all rating perspectives with children reporting the highest satisfaction. Partners were more satisfied than parents with mental illness with their current overall HRQoL. About half of the partner sample reported any problems with pain/discomfort and one third of the partners reported any problems with anxiety/depression.

Table 34. Characteristics of parents with mental illness (fourth research objective)

Characteristics	*n* (%)	*M* (*SD*)	Possible Score Range
Parents with mental illness			
HRQoL (EQ-5D-3L)[1]			
Mobility (any problems)	48 (23.1%)		1-2
Self-care (any problems)	55 (26.4%)		1-2
Usual activities (any problems)	135 (64.9%)		1-2
Pain/ discomfort (any problems)	143 (68.8%)		1-2
Anxiety/depression (any problems)	183 (88.0%)		1-2
VAS		54.22 (19.67)	0-100
Index		0.56 (0.22)	-0.21-1

Note. *n* = 208 parents with mental illness. Questionnaire-related scores were based on raw data; for details, see text (Methods). [1] based on self-reports of parents with mental illness.

Table 35. Characteristics of children and adolescents aged 8-18 years (fourth research objective)

Characteristics	*n* (%)	*M* (*SD*)	Possible Score Range
Children aged 8-18 years			
HRQoL (child self-report)[1]			
KIDSCREEN-10 index		37.84 (6.71)	10-50
KIDSCREEN-27, physical well-being		15.04 (3.66)	5-25
KIDSCREEN-27, mental health		26.45 (5.91)	7-35
KIDSCREEN-27, autonomy and parents		27.49 (5.32)	7-35
KIDSCREEN-27, social support and peers		15.81 (3.62)	4-20
KIDSCREEN-27, school environment		14.72 (3.48)	4-20
HRQoL (mentally ill parent proxy-report)[2]			
KIDSCREEN-10 index		36.60 (5.70)	10-50
KIDSCREEN-27, physical well-being		15.64 (3.53)	5-25
KIDSCREEN-27, mental health		25.39 (4.68)	7-35
KIDSCREEN-27, autonomy and parents		26.72 (4.41)	7-35
KIDSCREEN-27, social support and peers		14.00 (3.43)	4-20
KIDSCREEN-27, school environment		14.32 (3.42)	4-20
HRQoL (partner proxy-report)[3]			
KIDSCREEN-10 index		37.74 (5.55)	10-50
KIDSCREEN-27, physical well-being		15.68 (3.40)	5-25
KIDSCREEN-27, mental health		26.37 (5.05)	7-35
KIDSCREEN-27, autonomy and parents		27.83 (4.12)	7-35
KIDSCREEN-27, social support and peers		14.10 (3.49)	4-20
KIDSCREEN-27, school environment		14.68 (3.31)	4-20

Note. *n* = 198 children and adolescents aged 8-18 years. Questionnaire-related scores were based on raw data; for details, see text (Measures). [1] based on child self-reports. [2] based on the mentally ill parent' proxy-reports. [3] based on the partner/caregiver's proxy-report.

Table 36. Characteristics of partners (fourth research objective)

Characteristics	*n* (%)	*M* (*SD*)	Possible Score Range
Partners			
HRQoL (EQ-5D-3L) [1]			
Mobility (any problems)	22 (15.6%)		1-2
Self-care (any problems)	4 (2.8%)		1-2
Usual activities (any problems)	29 (20.6%)		1-2
Pain/ discomfort (any problems)	71 (50.4%)		1-2
Anxiety/depression (any problems)	46 (32.6%)		1-2
VAS		74.76 (19.05)	0-100
Index		0.81 (0.16)	-0.21-1

Note. *n* = 141 partners. [1] based on self-reports of partners. Questionnaire-related scores were based on raw data; for details, see text (Methods).

Abstract

Families affected by parental mental illness report on average lower HRQoL than families from the general population due to high physical, psychological, social and financial burdens. Research is still limited although the assessment of HRQoL is crucial to gain a holistic perspective of a person's well-being beyond mental health and to evaluate the effectiveness of clinical interventions. The investigation of modifiable HRQoL determinants can help to formulate therapeutic goals that meet the families' individual needs.

The analyses were based on baseline data of the randomized controlled multicenter study CHIMPS (BMBF). The overall project sample consisted of *n* = 216 families with *n* = 216 parents with mental illness, *n* = 338 children and adolescents aged 1-19 years, and *n* = 145 partners. The HRQoL of parents was assessed with the EQ-5D-3L, that of the children with the KIDSCREEN-27/10. HRQoL determinants that were considered for the analyses included mental and physical health, coping family functioning, social support, age and gender. Data analyses was based on multiple perspectives and comprised descriptive statistics, comparisons of binary probabilities and mean values, regression analyses and intraclass correlation coefficients (ICC) for analyzing child-parent agreement. To meet the complex demands of family clusters, mixed models were used when the ICC exceeded a critical value.

On average, families affected by parental mental illness reported significantly lower HRQoL than the general population, particularly regarding mental and physical aspects. In addition, parents reported dissatisfaction with occupational, familial, and social activities. Higher HRQoL of parents was primarily related to physical and mental health, and secondarily to adaptive coping, social support and being male. From the parents' perspective, significantly higher child HRQoL was primarily associated with mental health, social support, and a young age, and secondarily with the parental symptom burden and coping. Higher self-reported child HRQoL was related to the children's mental health, social support, and family functioning. The HRQoL of family members was weakly to moderately correlated with highest correlations being observed between children and parents when HRQoL was assessed from the same rating perspective. Clinicians and policymakers should increase the access to effective help offers for families affected by parental mental illness to improve their HRQoL and to identify individuals in need for further treatment, which may in turn avert higher treatment costs in the future. The results imply that interventions are most likely to improve the families' HRQoL when focusing next to the improvement of mental and physical health on family functioning, social connectedness, and adaptive coping resources.

Predominant moderate child-parent agreement on the KIDSCREEN-27/10 indicate that parent proxy-reports can be a useful addition to the children's perspectives. The results of the regression analyses can guide clinicians to anticipate family constellations of high disagreement (e.g., in dysfunctional families). The utility of the EQ-5D should be a consideration of the benefits (e.g., timesaving) and

drawbacks (e.g., limited coverage of HRQoL determinants relevant for families affected by mental illness).

Zusammenfassung

Familien psychisch kranker Eltern weisen im Vergleich zu Familien in der Allgemeinbevölkerung aufgrund hoher psychischer, physischer, sozialer und finanzieller Belastungen im Durchschnitt eine verminderte Lebensqualität auf. Obwohl die Erfassung der Lebensqualität entscheidend zu einer holistischen Perspektive in Hinblick auf das Wohlergehen einer Person jenseits der psychischen Gesundheit beiträgt und mit der Messung der Lebensqualität Interventionen evaluiert werden können, ist Forschung diesbezüglich immer noch limitiert. Die Erforschung modifizierbarer Determinanten ist für die Formulierung adäquater therapeutischer Ziele von Bedeutung.

Die Analysen basierten auf Ausgangsdaten (Baseline) der randomisiert kontrollierten multizentrischen CHIMPS (BMBF) Studie. Insgesamt wurden n = 216 Familien bestehend aus n = 216 psychisch kranken Elternteilen, n = 338 Kindern und Jugendlichen zwischen 1-19 Jahren und n = 145 Partner rekrutiert. Lebensqualität wurde mit dem EQ-5D-3L (Eltern) und dem KIDSCREEN-27/10 (Kinder) erfasst. Die analysierten Determinanten der Lebensqualität umfassten mentale und physische Gesundheit, Krankheitsverarbeitung, Familienfunktionalität, soziale Unterstützung, Alter und Geschlecht. Die multiperspektivische Datenevaluation beinhaltete neben deskriptiven Statistiken, Vergleiche von binären Wahrscheinlichkeiten und Mittelwerten, Regressionsanalysen und Intraklassen Korrelationskoeffizienten (ICC). Um die komplexen Herausforderungen der Familiencluster in der Datenanalyse zu berücksichtigen ($ICC \geq .10$) wurden z.T. gemischte Modelle eingesetzt.

Familien psychisch kranker Eltern berichteten im Durchschnitt eine signifikant niedrigere Lebensqualität als die Allgemeinbevölkerung, insbesondere in Bezug auf die mentale und physische Lebensqualität. Darüber hinaus äußerten Eltern Unzufriedenheit bezüglich beruflicher, familiärer und sozialer Aspekte. Eine höhere elterliche Lebensqualität war primär assoziiert mit physischer und mentaler Gesundheit sowie sekundär mit adaptiver Krankheitsverarbeitung, sozialer Unterstützung und dem männlichen Geschlecht. Eine höhere kindliche Lebensqualität war aus Sicht der Eltern primär assoziiert mit der mentalen Gesundheit der Kinder, soziale Unterstützung, einem jüngeren Alter und sekundär mit elterlicher Symptombelastung und Krankheitsverarbeitung. Aus Sicht der Kinder hing die kindliche Lebensqualität vor allem mit ihrer psychischen Gesundheit, sozialen Unterstützung und Familienfunktionalität zusammen. Die Lebensqualität der Familienmitglieder wies insgesamt leichtgradige bis moderate Korrelationen auf. Höhere Korrelationen fanden sich zwischen Kindern und Eltern, vor allem bei Betrachtung der gleichen Urteilerperspektive.

Kliniker und Gesetzgeber sollten betroffene Familien den Zugang zu effektiven Hilfsangeboten erleichtern, um ihre Lebensqualität zu verbessern. Wichtig sind außerdem die frühe Identifizierung und Behandlung von sehr belasteten Personen, um spätere psychische und finanzielle (hohe Behandlungskosten) Folgen zu vermeiden. Laut den Resultaten verbessern vor allem Interventionen die familiäre Lebensqualität, die neben der mentalen und physischen Gesundheit die Familienfunktionalitität, soziale Unterstützung und adaptive Krankheitsverarbeitung fördern. Die

überwiegend moderate Kind-Eltern Urteilübereinstimmung beim KIDSCREEN-27/10 zeigt, dass die Elternperspektive eine informative Ergänzung zur Selbstperspektive der Kinder sein kann. Die Resultate können Klinikern und Forschern helfen, Situationen mit niedriger Übereinstimmung zu antizipieren (z.B. in dysfunktionalen Familien). Der Nutzen des EQ-5D beinhaltet eine Abwägung der Vor- (z.B. zeitsparend) und Nachteile (z.B. begrenzte Abdeckung von Themen, die für Familien psychisch kranker Eltern relevant sind).

List of Publications

Publication

Radicke, A., Barkmann, C., Adema, B., Daubmann, A., Wegscheider, K., & Wiegand-Grefe, S. (2021). Children of Parents with a Mental Illness: Predictors of Health-Related Quality of Life and Determinants of Child–Parent Agreement. International journal of environmental research and public health, 18(2), 379. https://doi.org/10.3390/ijerph18020379

Own contribution to the publication

Alina Radicke was responsible for the conceptualization, literature review and formal analysis of the research objectives as well as for visualizing, writing, and editing the original draft, coordinating the publication process and successfully revising the manuscript.

International Journal of
*Environmental Research
and Public Health*

MDPI

Article

Children of Parents with a Mental Illness: Predictors of Health-Related Quality of Life and Determinants of Child–Parent Agreement

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Abstract: (1) Background: Health-related quality of life (HRQoL) is frequently reduced in children of parents with a mental illness (COPMI). Child self- and parent proxy-ratings vary with raters' characteristics and facets of HRQoL. This study aimed at analyzing risk and protective factors associated with HRQoL in COPMI, and at examining the magnitude, direction, and predictors of child–parent agreement. (2) Methods: Analyses were based on baseline data of the German CHIMPS (children of parents with a mental illness) project with $n = 134$ parents diagnosed with mental illness and $n = 198$ children and adolescents aged 8 to 18 years. (3) Results: Both children and parents reported significantly lower HRQoL than the reference population, particularly for the child's physical and psychological well-being. Parents' proxy-report indicated a lower HRQoL than the children's self-report. Child and parental psychopathology, social support, and the child's age significantly predicted HRQoL. Interrater agreement was satisfactory and better for observable aspects like physical well-being and school environment. The child's gender-identity and mental health significantly predicted child–parent agreement. (4) Conclusions: Parental psychopathology significantly reduces children's HRQoL. Interventions should promote resilience in children by targeting risk and protective factors. Child–parent agreement emphasizes the need to obtain both self- and proxy-reports, whenever possible.

Keywords: children's health-related quality of life; parents; mental disorder; child–parent agreement; children of parents with a mental illness; family psychology

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Citation: Radicke, A.; Barkmann, C.; Adema, B.; Daubmann, A.; Wegscheider, K.; Wiegand-Grefe, S. Children of Parents with a Mental Illness: Predictors of Health-Related Quality of Life and Determinants of Child–Parent Agreement. *Int. J. Environ. Res. Public Health* **2021**, *18*, 379. https://doi.org/10.3390/ijerph18020379

Received: 4 December 2020
Accepted: 2 January 2021
Published: 6 January 2021

1. Introduction

About one in five minor children has at least one parent with a mental illness [1]. Mental illness in primary caregivers can impair the psychosocial development of the offspring. The psychological burden of parental mental illness may not only lead to emotional and behavioral difficulties in children, but also has a more general influence on the children's social relationships, interests, and academic environment, and thus may affect the children's overall well-being and life satisfaction. Health-related quality of life (HRQoL) has been increasingly considered as an outcome criterion for children and adolescents to determine the burden of such demanding family conditions [2]. It has been defined as a subjective, multidimensional construct that compromises physical, psychological and social well-being [3]. Research has consistently shown that HRQoL of COPMI is reduced across different types of parental mental illness [4–8]. To prevent adverse psychosocial consequences for COPMI and to improve their HRQoL, it is crucial to examine risk and protective factors that are linked to the children's well-being. Results can help to develop more efficient clinical interventions. Although self-reports are valuable sources of information, parent proxy-reports are often used as a replacement [9]. When parents suffer from mental disorders, they tend to assess their offspring's HRQoL lower than the children do [10]. Discrepancies between children's self- and parents' proxy-reports can also originate from the raters' relationship and demographic characteristics (e.g., age, gender-identity), as well as from the observability of the HRQoL domain. Investigating the extent of child–parent agreement and to identify predictors of disagreement is crucial, especially when parents are responsible to make health care decisions for their children, and when their perspective on child HRQoL differs from the child's own rating [9,11].

1.1. Predictors of HRQoL in COPMI

The dynamic interaction between both risk and protective factors determines the children's ability to adapt and recover from adverse psychosocial outcomes associated with parental mental illness [12–14]. Some of the most relevant risk and protective factors of HRQoL in COPMI include symptom severity of parental psychopathology and disease coping, emotional and behavioral difficulties in COPMI, the family's mental health literacy, family functioning, social support, and child-related demographic variables. Parental psychopathology has implications for all family members. COPMI are more likely than their peers to experience unstable home environments, family conflicts, and a higher daily strain [15]. Depending on the nature and severity of symptoms, parenting skills can be impaired due to psychopathology and may result in reduced involvement with the child, insensitivity, hostility, rejection, neglect, and potential abuse [15,16]. Difficulties in parenting can also lead to insecure attachment, emotional dysregulation, negative emotionality, and pathological coping strategies, as well as psychopathology in the offspring irrespective of the children's age [16,17]. Difficulties in parenting have been observed across different types of mental disorders, although most research has been conducted on depression. Parental depression has been associated with a markedly diminished interest in most activities, lack of energy, irritability and depressed mood, which tend to manifest in less child–parent interactions characterized by reduced empathy, verbal communication, and emotional availability, as well as a negative family discord [18–21]. The way parents appraise and cope with stressors like mental illness has both an impact on their own [22,23] and their offspring's mental health and quality of life [24]. Research suggests that parents with a mental illness who practice adaptive coping strategies show better adaptions to their mental health condition [22], mitigate the negative outcomes of family burden and stigmatization [25], and improve HRQoL in their offspring [24].

COPMI have a significantly higher psychiatric risk than children with healthy parents due to various genetic and psychological vulnerabilities [26]. When children suffer from psychiatric symptoms, quality of life is poor and even lower compared to physical samples [27,28]. The World Health Organization (WHO) concluded based on a survey with over 51,507 participants that children with one parent with a mental illness have a 1.8 to 2.9 (odds ratio) times higher general psychiatric risk than the general population. When both parents were affected, the risk even raised from 2.2 to 4.6 (odds ratio) [29]. COPMI have a seven-fold risk to somaticize [30] and express psychiatric symptoms by physical complaints like headaches, fatigue, or stomachaches [8], which lowers satisfaction with physical aspects of HRQoL [8,29–32]. Caregivers' depressive symptoms also reduce a child's health-promoting behavior like healthy eating and exercise [32], which may result in dissatisfaction with physical activities and health. High health literacy in parents, which is characterized by a high amount of knowledge about the recognition, management, and prevention of mental disorders, can serve as a protective factor for the children's mental health and promote their resilience [33].

Family functioning is an important determinant of quality of life in children and adolescents [34–36]. Research has consistently shown that family burden is higher in families with parental psychopathology across various psychiatric diagnoses e.g., depression [37], bipolar disorder [38], psychosis [39], and anxiety disorders [40]. Parental psychopathology may be associated with family discord, lower levels of expressiveness and affective involvement, impaired communication [37–40], and adverse psychosocial outcomes like unemployment and financial difficulties that strain family relations [15]. The extent of family burden has been determined by clinical characteristics such as symptom type and severity, a higher relapse frequency, and the severity of impaired functioning [41].

In line with the stress-buffering hypothesis, social support has been positively associated with HRQoL and psychological well-being and in children and adolescents [34,42,43]. Social support from extrafamilial sources may increase in importance, when family functioning is low. However, especially children from conflict-ridden families had difficulties to find and maintain friends and were viewed less favorably by their peers [44]. About one third of families with parental psychopathology perceive the social support they receive as insufficient [30].

The most consistent results regarding child-related demographic predictors of HRQoL exist regarding the children's age and gender-identity. In a sample with 22,827 European participants, 8–11 years old children reported higher HRQoL than adolescents aged 12–18. Boys reported higher HRQoL than girls in most HRQoL aspects [45]. Similar age-related decreases in life satisfaction and gender-identity-related differences, especially during adolescence, have been reported in other studies [6,8,46].

1.2. Interrater Agreement on Child HRQoL Measures

Self-reports are generally the principle method with regard to the assessment of subjective experiences of health and well-being [34]. Nonetheless, it is still common that parents provide proxy-reports on their children's HRQoL, whereas the children's perspective is either neglected or surveyed only in addition [9]. This practice has been justified for younger age groups by the assumption that younger children lack sufficient cognitive and linguistic abilities to understand and interpret HRQoL questions by themselves [9]. They may also lack the ability to adopt a long-term perspective of events and consequences and have a restricted attention span [34]. Contrary to these assumptions, studies have demonstrated that even young children, who are given the opportunity to assess their own HRQoL with age-appropriate instruments, are able to understand questions and produce valid and reliable answers from the age of eight years onwards [47].

Interrater agreement on standardized child HRQoL measures may vary due to child and parent characteristics as well as with the HRQoL domain of interest. Research indicates that the child's mental and physical health is linked to interrater-agreement on HRQoL measures [9,48,49]. Parents of healthy children over-report the children's HRQoL compared to parents of children with physical or mental illness [9,48,49]. Parents of children with chronic conditions under-report their offspring's quality of life [50]. When children suffer from physical rather than mental illness, child–parent agreement on HRQoL measures is higher [51], probably due to the better observability of physical symptoms [9,49,52]. Inconsistent results have been reported for child-related age and gender-identity effects on child–parent agreement [53–56]. It has been suggested that interrater agreement may vary for certain HRQoL domains like physical or emotional well-being in different developmental stages, thereby explaining the inconsistency [49].

With regard to the parent's characteristics, research indicates that the parent's relationship with the child as well as own perceptions of mental health and HRQoL are more predictive of child–parent agreement than the parent's sociodemographic attributes. High family functioning characterized by high levels of intimacy and a high amount of shared time increases concordance between children and their parents [57,58]. The higher parents assessed their mental health condition [59,60] and HRQoL [11], the higher they rated their children's well-being too, suggesting that parents project their own feelings on judgments about their children's functioning [53]. Parents make more accurate proxy ratings when they assess objective and observable aspects of their children's well-being (e.g., physical functioning, externalizing behavior) and have more difficulties with subjective and invisible aspects (e.g., the children's feelings, internalizing behavior) [45]. The discrepancies reported in emotion-focused HRQoL items appear to become more discordant in adolescence compared to younger age groups [61], probably because adolescents spend more time in extrafamilial settings and prefer to discuss emotional needs with peers [49].

There are several research gaps that we aimed to overcome with this study. First, HRQoL has predominantly been investigated in adults with physical or mental disorders, or in normative samples [8,62]. Some studies have examined the HRQoL of COPMI but have either based their conclusions on bivariate correlational research, or focused solely on a few risk factors, thereby neglecting the multidimensionality of HRQoL. The inclusion of multiple predictors and regression analyses to draw conclusions on HRQoL in COPMI is still exceptional [63]. Results from multiple regression analyses may raise awareness for COPMI and allow the development and improvement of appropriate psychological interventions. Second, no study has yet, as far as we know, systematically investigated child–parent agreement regarding the children's HRQoL when the parents were formally diagnosed with mental disorders according to the ICD-10 classification criteria. Moreover, although research has increasingly considered the children's perspective in the last two decades, studies have mainly assessed the children's HRQoL with parent–proxy ratings [11] and had several methodological limitations [11,50]. Small sample sizes have frequently prevented systematic analyses beyond bivariate correlational research, thereby limiting causal inference [50]. Agreement has usually been assessed with Pearson's product–moment correlation coefficient, although it is not a measure of agreement [52,64]. A more appropriate statistic of agreement would be the intraclass correlation coefficient (ICC) [65]. In addition, predictors of agreement have rarely been investigated in multivariate analyses, which would enable researchers to glean a more realistic picture of child–parent agreement [50].

The aims of this study were, therefore first, to compare the HRQoL of COPMI with a reference population, thereby considering the children's and the parents' perspective. The second objective is to examine predictors of global child-related HRQoL. The third objective was the investigation of the magnitude and direction of child–parent agreement on specific and global HRQoL. Lastly, we aimed at examining variables predicting (dis)agreement with multiple child- and family-related variables. We expected that children and their parents with a mental illness reported both lower global and specific HRQoL than the reference population. Moreover, we assumed that child and parent psychopathology, low social support, a female gender-identity, older age, family dysfunction, maladaptive coping behavior were associated with lower global HRQoL in COPMI. Furthermore, we hypothesized that child–parent agreement was only of moderate size, and that disagreement on global HRQoL was predicted by child and parental psychopathology, family functioning, parental HRQoL, and the child's age and gender-identity.

2. Methodology

2.1. Study Design

Analyses for the present study were conducted using the baseline data (gathered 2014 to 2017) of the randomized controlled CHIMPS (children of parents with a mental illness) project conducted in Germany and Switzerland. This project collected data primarily on the mental health status and HRQoL of parents with a mental illness, their partners, and children by means of standardized psychometric questionnaires to evaluate the effectiveness of the manualized family intervention "CHIMPS". The aims of the intervention were the reduction of psychopathology in children and the enhancement of their long-term quality of life, as well as the introduction of remarkable children and adolescents to an early intervention. A detailed description of the intervention is provided in the CHIMPS manual [66]. Parents with mental disorders were recruited in multiple German and Swiss inpatient psychiatric hospitals based on the patients' and their families' availability and willingness to take part. Ethical approval has been provided by the Ethics Committee of the regional Medical Association (Hamburg, Germany) under the number PV4744. All participants were informed about study aims and procedures. Their participation in the study and the family intervention CHIMPS was voluntary and confidential. Written informed consent was obtained from all adult participants. Written assents of children under 18 years and the permission of their parents were received.

2.2. Participants

The overall sample of the project compromised 214 families with 214 parents with a mental illness, 144 partners, and 335 children. Children outside the questionnaires' required age range (*n* = 136), and one remaining child with more than 30% missing data were excluded. The resulting final sample under analysis included *n* = 134 parents with a mental illness and *n* = 198 children and adolescents aged 8–18. Participation required parents to be diagnosed by clinicians with at least one ICD-10 psychiatric diagnosis. Participants with acute symptoms requiring inpatient treatment were excluded and referred to acute health services. Tables 1 and 2 display the sample characteristics.

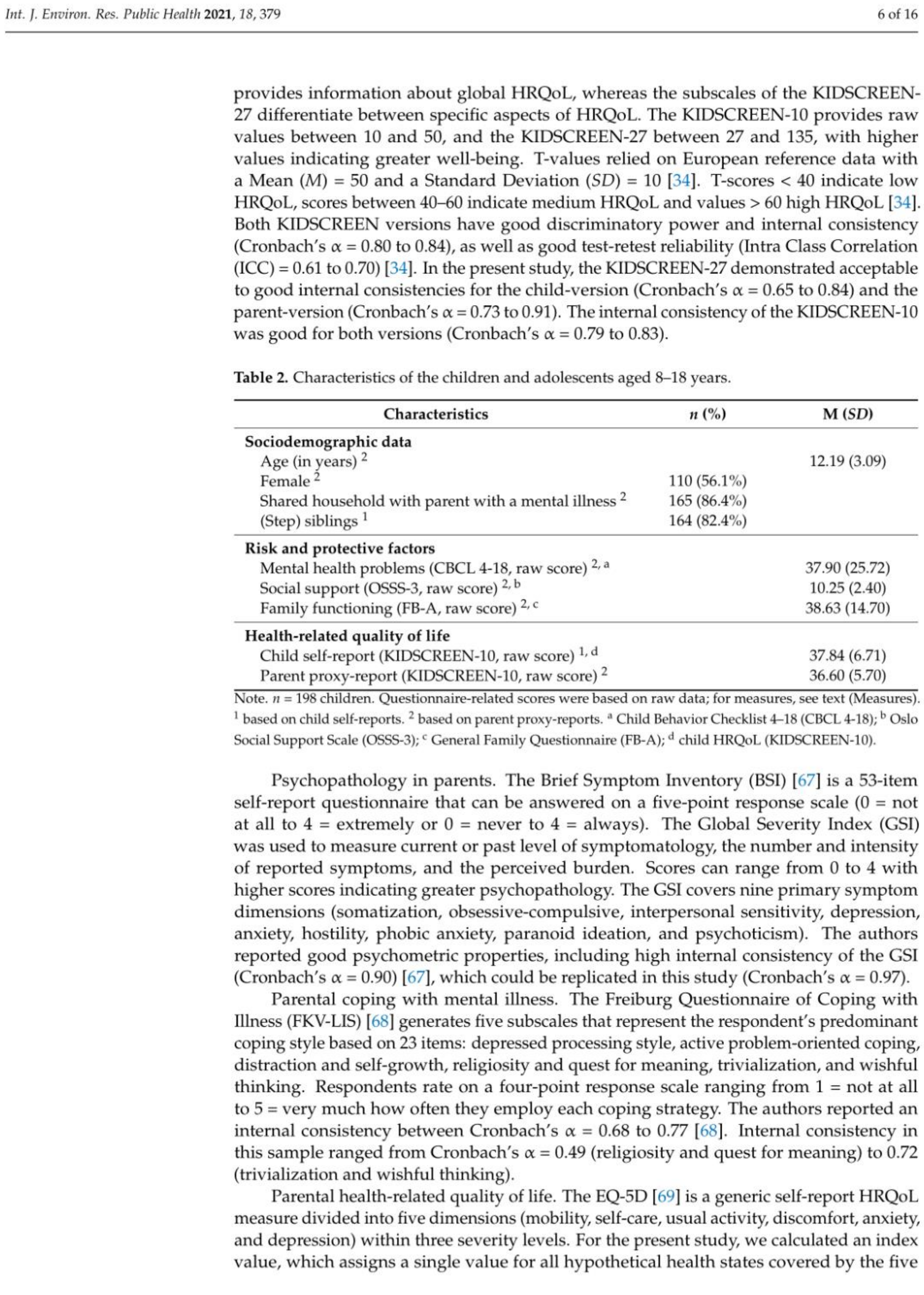
Table 1. Characteristics of the parents with a mental illness.

Characteristics	*n* (%)	M (*SD*)
Sociodemographic data		
Age (in years) [1]		41.59 (6.77)
Female [1]	102 (76.1%)	
Number of children [1]		2.14 (0.94)
Married [1]	75 (56.4%)	
School education [1]		
11–13 years education	39 (30.5%)	
10 years education	60 (46.9%)	
9 years education	26 (20.3%)	
No secondary education	3 (2.3%)	
Risk and protective factors		
Psychiatric diagnosis (ICD-10) [2, a]		
F10–F19	2 (1.5%)	
F20–F29	4 (3.0%)	
F30–F39	75 (56.0%)	
F40–F48	15 (11.2%)	
F60–F69	37 (27.6%)	
F90–F98	1 (0.7%)	
Comorbidity (ICD-10) [2, a]	56 (41.8%)	
Symptom burden (BSI, raw score) [1, b]	109 (83.2%)	1.36 (0.72)
Parental Coping (FKV-LIS, raw score) [1, c]		
Depressed processing style		15.43 (3.79)
Active problem-oriented coping		16.12 (3.78)
Distraction and self-growth		13.85 (3.31)
Religiosity and quest for meaning		13.11 (3.38)
Trivialization and wishful thinking		7.87 (3.13)
Parental health-related quality of life (EQ-5D, raw score) [1, d]		0.57 (0.22)

Note. *n* = 134. Questionnaire-related scores were based on raw data; for measures, see text (Measures). [1] based on parent self-reports. [2] based on proxy-ratings by clinicians. [a] International Classification of Diseases (ICD-10) codes: mental and behavioral disorders due to psychoactive substance use (F10–F19), schizophrenia, schizotypal, and delusional disorders (F20–F29), mood (affective) disorders (F30–F39), neurotic, stress-related and somatoform disorders (F40–F48), disorders of adult personality and behavior (F60–F69), behavioral and emotional disorders with onset usually occurring in childhood and adolescence (F90–F98); [b] Brief Symptom Inventory (BSI); [c] Freiburg Questionnaire of Coping with Illness (FKV-LIS); [d] parental HRQoL (EQ-5D).

2.3. Measures

Health-related quality of life. The German self- and proxy-report version of the KIDSCREEN-27 and KIDSCREEN-10 was administered [34]. It covers 27 items of five domains: physical well-being (e.g., "Have you felt fit and well?"), psychological well-being, autonomy and parents, social support and peers, and school environment on a five-point response scale (1 = not at all to 5 = extremely or 1 = never to 5 = always). The KIDSCREEN-10 index contains 10 items and is derived from the 27-item version. The index



provides information about global HRQoL, whereas the subscales of the KIDSCREEN-27 differentiate between specific aspects of HRQoL. The KIDSCREEN-10 provides raw values between 10 and 50, and the KIDSCREEN-27 between 27 and 135, with higher values indicating greater well-being. T-values relied on European reference data with a Mean (*M*) = 50 and a Standard Deviation (*SD*) = 10 [34]. T-scores < 40 indicate low HRQoL, scores between 40–60 indicate medium HRQoL and values > 60 high HRQoL [34]. Both KIDSCREEN versions have good discriminatory power and internal consistency (Cronbach's α = 0.80 to 0.84), as well as good test-retest reliability (Intra Class Correlation (ICC) = 0.61 to 0.70) [34]. In the present study, the KIDSCREEN-27 demonstrated acceptable to good internal consistencies for the child-version (Cronbach's α = 0.65 to 0.84) and the parent-version (Cronbach's α = 0.73 to 0.91). The internal consistency of the KIDSCREEN-10 was good for both versions (Cronbach's α = 0.79 to 0.83).

Table 2. Characteristics of the children and adolescents aged 8–18 years.

Characteristics	*n* (%)	M (*SD*)
Sociodemographic data		
Age (in years) ^{2}		12.19 (3.09)
Female ^{2}	110 (56.1%)	
Shared household with parent with a mental illness ^{2}	165 (86.4%)	
(Step) siblings ^{1}	164 (82.4%)	
Risk and protective factors		
Mental health problems (CBCL 4-18, raw score) ^{2,a}		37.90 (25.72)
Social support (OSSS-3, raw score) ^{2,b}		10.25 (2.40)
Family functioning (FB-A, raw score) ^{2,c}		38.63 (14.70)
Health-related quality of life		
Child self-report (KIDSCREEN-10, raw score) ^{1,d}		37.84 (6.71)
Parent proxy-report (KIDSCREEN-10, raw score) ^{2}		36.60 (5.70)

Note. *n* = 198 children. Questionnaire-related scores were based on raw data; for measures, see text (Measures). ^{1} based on child self-reports. ^{2} based on parent proxy-reports. ^{a} Child Behavior Checklist 4–18 (CBCL 4-18); ^{b} Oslo Social Support Scale (OSSS-3); ^{c} General Family Questionnaire (FB-A); ^{d} child HRQoL (KIDSCREEN-10).

Psychopathology in parents. The Brief Symptom Inventory (BSI) [67] is a 53-item self-report questionnaire that can be answered on a five-point response scale (0 = not at all to 4 = extremely or 0 = never to 4 = always). The Global Severity Index (GSI) was used to measure current or past level of symptomatology, the number and intensity of reported symptoms, and the perceived burden. Scores can range from 0 to 4 with higher scores indicating greater psychopathology. The GSI covers nine primary symptom dimensions (somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism). The authors reported good psychometric properties, including high internal consistency of the GSI (Cronbach's α = 0.90) [67], which could be replicated in this study (Cronbach's α = 0.97).

Parental coping with mental illness. The Freiburg Questionnaire of Coping with Illness (FKV-LIS) [68] generates five subscales that represent the respondent's predominant coping style based on 23 items: depressed processing style, active problem-oriented coping, distraction and self-growth, religiosity and quest for meaning, trivialization, and wishful thinking. Respondents rate on a four-point response scale ranging from 1 = not at all to 5 = very much how often they employ each coping strategy. The authors reported an internal consistency between Cronbach's α = 0.68 to 0.77 [68]. Internal consistency in this sample ranged from Cronbach's α = 0.49 (religiosity and quest for meaning) to 0.72 (trivialization and wishful thinking).

Parental health-related quality of life. The EQ-5D [69] is a generic self-report HRQoL measure divided into five dimensions (mobility, self-care, usual activity, discomfort, anxiety, and depression) within three severity levels. For the present study, we calculated an index value, which assigns a single value for all hypothetical health states covered by the five dimensions. An index of 1 represents the best possible state of health, while value 0 represents the opposite. The EQ-5D is a moderately valid instrument to assess HRQoL in adults with mental disorder and has reasonable discriminative ability and reliability [69]. Here, the internal consistency of the index was Cronbach's $\alpha = 0.28$.

Psychopathology in children. The Child Behavior Checklist 4–18 [70,71] is a widely used instrument to rate maladaptive emotional and behavioral problems in children aged 4–18 years on a three-point response scale from 0 = not at all to 2 = often. The parent-version has 118 items. It generates eight syndrome scales (withdrawn, somatic complaints, anxious/depressed, social problems, thought problems, attention problems, delinquent behavior, aggressive behavior) and a total score, which was used for calculations in this study. The total score can range from 0 to 111 with higher values indicating greater psychopathology in children. Psychometric validity and reliability have been established in numerous clinical and non-clinical studies [70,71]. In the present study, the total score of the CBCL-4-18 parent version demonstrated excellent internal consistency with Cronbach's $\alpha = 0.95$.

Family functioning. The General Family Questionnaire (Allgemeiner Familienbogen; FB-A) has 40 items [72]. This study focused on the total score, which reflects overall family functioning and is the sum of seven subscales (task fulfillment, role behavior, communication, emotionality, affectivity of relations, control, values, and norms). Items are rated on a four-point response scale ranging from 0 = completely true to 3 = not true at all. The total score can range from 0 to 120. Higher scores reflect greater family dysfunction. The authors reported an internal consistency of $\alpha = 0.46$–0.80, with $\alpha > 0.60$ for most subscales [72], which could be replicated in this study (Cronbach's $\alpha = 0.63$ to 0.74). Here, the total score had an excellent internal consistency of $\alpha = 0.93$.

Social support. The Oslo Social Support Scale (OSSS-3) [73] consists of three items asking parents to proxy-report for their children the number of close confidants, the sense of concern from other people, and the relationship with neighbors and the accessibility of practical help. The scale of the first item has been adapted for study purposes from a 4 to 5-point response scale (1 = none, 2 = 1–2, 3 = 3–4, 4 = 5–6 and 5 = more than 6). The total score is calculated by summarizing those three items. It ranges from 3 to 15 with higher scores indicating greater social support. The OSSQ-3 has demonstrated good validity and reliability in a representative sample with 2524 German participants [74]. The modified version in this study demonstrated an adequate internal consistency of $\alpha = 0.69$.

2.4. Data Analysis

We first examined whether our sample's HRQoL differentiated significantly from the reference population [34]. Normative data were considered for both the child- and proxy reports. As children within families were more correlated than children from different families (ICC ≥ 0.10), differences were analyzed with linear mixed models. For the same reason, the impact of multiple predictors on child proxy-rated HRQoL was evaluated with linear mixed models. Coefficients, standard errors, and p-values were calculated for each predictor, and overall model fit was reported. To estimate child–parent agreement on HRQoL measures, ICC estimates were calculated with a two-way mixed effects model based on single ratings. ICC estimates were defined by both consistency and absolute agreement. According to Cicchetti's guidelines, ICC < 0.4 are classified as poor, 0.40–0.59 as fair, 0.60–0.74 as good, and 0.75–1.00 as excellent reliability [75]. Multiple linear regression was performed to analyze the impact of various predictors on total disagreement of HRQoL between children and their parents with a mental illness. Total disagreement was calculated by subtracting the children's index from the parents' index. Family clusters were not considered as ICC values were <0.10. The scores of both regression analyses were based on raw values assessed by parents with a mental illness. All metric predictors were grand mean-centered. Questionnaire-related missings were imputed according to the Expectation–Maximization algorithm (EM) [76]. Statistical significance was set at $\alpha \leq 0.05$ two-sided. All statistical analyses were performed using IBM SPSS 25 (IBM, Armonk, NY, USA).

3. Results

3.1. Descriptive Statistics

The sample compromised 134 families (n = 102 mothers with a mental illness, n = 32 fathers with a mental illness, n = 198 children and adolescents). Characteristics of parents and children are described in Tables 1 and 2, respectively. Parents with a mental illness had a mean age of M = 41.59 (SD = 6.77). About half of the sample was married. Most parents had 10 to 13 years of school education. The most prominent primary psychiatric ICD-10 diagnoses were mood (affective) disorders (F30–F39, e.g., major depressive disorder), followed by disorders of adult personality and behavior (F60–F69, e.g., paranoid personality disorder), and neurotic, stress-related and somatoform disorders (F40–F48, e.g., phobias, obsessive-compulsive disorder). Less prevalent were schizophrenia, schizotypal, and delusional disorders (F20–F29, e.g., delusional disorder), mental and behavioral disorders due to psychoactive substance use (F10–F19, e.g., alcohol dependence) and behavioral and emotional disorders with onset usually occurring in childhood and adolescence (F90–F98, e.g., attention deficit hyperactivity disorder). Almost half of the parents had comorbid psychiatric ICD-10 diagnoses. Most parents reported a psychologically remarkable symptom burden (BSI raw score $\geq$ 0.62). Parents with a mental illness frequently employed active problem-oriented coping, followed by a depressed processing style. Parents reported moderate satisfaction with current health. The n = 198 participating children and adolescents had a mean age of M = 12.19 (SD = 3.09) years. Boys and girls were equally represented. Most of the children shared the household with their parents with a mental illness and had either biological or step siblings. The sample's mean raw value of the CBCL 4-18 was M = 37.90 (SD = 25.72), and M = 10.25 (SD = 2.40) on the OSSS-3. Children and adolescents self-reported slightly higher HRQoL on the KIDSCREEN-10 than their parents.

3.2. HRQoL of Children and Adolescents from the Children's and the Parents' Perspective

Tables 3 and 4 show the average values of HRQoL in COPMI from the parents' and the children's report, respectively. Parents' proxy reports for their children's global and specific HRQoL were lower than the assessments of parents from the reference sample (M = 50, SD = 10). Differences were significant for the KIDSCREEN-10 index and all KIDSCREEN-27 subscales, except for autonomy and parents (all $p < 0.01$). Mean values were rated lowest for psychological and physical well-being and highest for autonomy and parents. Parents assessed their offspring's HRQoL lower than the children did on all aspects, except for physical well-being. On average, children self-reported both lower global and specific HRQoL than the reference population. Significant differences between the sample and the reference population were found for the index as well as for the subscales physical and psychological well-being (all $p < 0.01$). Both the children's and the parents' perspective can be considered to represent a medium HRQoL rating [34]. Children within families were more correlated than children from different families (ICC $\geq$ 0.10).

3.3. Prediction of HRQoL in Children and Adolescents

Table 5 shows the prediction of HRQoL in children and adolescents aged 8–18 years. Family clusters were considered in the analysis as children within families were more similar to each other than children from different families (ICC = 0.45). All calculations were based on raw values. Adding the predictors to the null model significantly improved the model fit (χ^2(df) = 98.98 (12), $p < 0.001$). Significant predictors of HRQoL were child psychopathology, social support, the child's age, and parental psychopathology (all $p < 0.05$). Lower HRQoL was associated with child and parental psychopathology, as well as older age in children. Social support was associated with higher HRQoL. Whereas the added child-related predictors in model 1 explained 53.41% of the residual variance, family-related predictors explained only 6.23%. The model had a significant amount of variation left unexplained by the information included. Nonetheless, the fit of model 1 was significantly better than the fit of the null model.

Table 3. Average HRQoL in children from the parents' perspective.

Categories	Model-Based		
	Adjusted Mean	95% CI	ICC
KIDSCREEN-27 Subscale			
Physical well-being	43.81 ***	(42.42, 45.22)	0.25
Psychological well-being	43.04 ***	(41.05, 45.04)	0.13
Autonomy and parents	48.61	(47.03, 50.20)	0.71
Social support and peers	46.63 **	(44.75, 48.51)	0.41
School environment	46.94 **	(45.18, 48.70)	0.25
KIDSCREEN-10 Index	44.09 ***	(42.57, 45.61)	0.40

Note. $n = 189$. CI = confidence interval, ICC = intraclass correlation coefficient; calculations were based on average T-scores and analyzed with a linear mixed model, for measures, see text (Measures). ** $p < 0.01$; *** $p < 0.001$.

Table 4. Average HRQoL in children from the children's perspective.

Categories	Model-Based		
	Adjusted Mean	95% CI	ICC
KIDSCREEN-27 Subscale			
Physical well-being	43.23 ***	(41.69, 44.78)	0.27
Psychological well-being	46.41 **	(44.39, 48.43)	0.33
Autonomy and parents	49.57	(47.79, 51.34)	0.16
Social support and peers	48.27	(46.42, 50.12)	*n*.a. [1]
School environment	49.13	(47.30, 50.97)	0.16
KIDSCREEN-10 Index	47.42 **	(45.59, 49.25)	0.33

Note. $n = 136$. CI = confidence interval, ICC = intraclass correlation coefficient; calculations were based on average T-scores and analyzed with a linear mixed model, for measures, see text (Measures). [1] The ICC could not be estimated and was thus set to zero. ** $p < 0.01$; *** $p < 0.001$.

Table 5. Prediction of HRQoL (KIDSCREEN-10, raw score) in children and adolescents aged 8–18 years.

Categories	Model 1	
	Coefficients	*SE*
Fixed Effects		
Intercept	30.06 ***	0.49
Child-related predictors		
Child psychopathology (CBCL 4-18, raw score)	−0.09 ***	0.01
Social support (OSSS-3, raw score)	0.72 ***	0.15
Female	0.94	0.62
Age (years)	−0.37 *	0.15
Age by gender-identity	0.10	0.19
Family-related predictors		
Parental psychopathology (BSI, raw score)	−1.62 **	0.61
Family functioning (FB-A, raw score)	−0.04	0.03
Parental coping (FKV-LIS, raw score)		
Depressed processing style	0.09	0.11
Active problem-oriented coping	−0.07	0.11
Distraction and self-growth	−0.22	0.13
Religiosity and quest for meaning	0.00	0.11
Trivialization and wishful thinking	0.16	0.13
Random Effects		
Variance of residuals	9.66 ***	1.98
Variance of intercepts	7.76 **	2.56
ICC	0.45	

Table 5. *Cont.*

Categories	Model 1	
	Coefficients	*SE*
Model Fit		
Deviance	1047.44	
χ^2(df)	98.98 (12) ***	
BIC	1057.71	

Note. $n = 183$. *SE* = standard error, ICC = intraclass correlation coefficient, χ^2(df) = chi-squared (degrees of freedom), BIC = Bayesian information criterion; all calculations were based on raw data and analyzed with a linear mixed model; all metric predictors were mean-centered; for measures, see text (Measures). * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

3.4. Child–Parent Agreement on HRQoL in Children and Adolescents

Table 6 displays the child–parent agreement on the children's HRQoL. Interrater agreement was significant for all global and specific aspects of HRQoL (all $p < 0.001$). ICC consistency and absolute agreement values ranged from 0.34 (social support and peers) to 0.49 (school environment), which indicates fair congruence between ratings.

Table 6. Child–parent agreement on HRQoL in children and adolescents aged 8–18 years.

Categories	ICC Consistency	ICC Absolute Agreement
	ICC (95% CI)	ICC (95% CI)
KIDSCREEN-27 Subscale		
Physical well-being	0.46 *** (0.31, 0.59)	0.46 *** (0.31, 0.59)
Psychological well-being	0.45 *** (0.30, 0.58)	0.43 *** (0.28, 0.56)
Autonomy and parents	0.42 *** (0.26, 0.55)	0.42 *** (0.26, 0.55)
Social support and peers	0.40 *** (0.24, 0.54)	0.34 *** (0.13, 0.51)
School environment	0.49 *** (0.35, 0.61)	0.49 *** (0.35, 0.61)
KIDSCREEN-10 Index	0.46 *** (0.31, 0.59)	0.45 *** (0.30, 0.58)

Note. $n = 127$. CI = confidence interval, ICC = intraclass correlation coefficient; for measures, see text (Measures). *** $p < 0.001$.

3.5. Predictors of Child–Parent Agrement on HRQoL in Children and Adolescents

The difference between child- and parent-reports was calculated to analyze the impact of various predictors on child–parent agreement on HRQoL in children. Predictors of total child–parent disagreement on HRQoL in children and adolescents are displayed in Table 7. Parents rated their offspring's HRQoL lower than the children did. The multiple regression model with all seven predictors explained 19.5% of the variance in the dependent variable. When the effects of all predictors are held constant, the rater show b = 3.84 deviation points. Significant predictors of disagreement were the child's psychopathology and the child's gender-identity (all $p < 0.05$). The difference between child- and parent-reports was smaller, when children were male and had psychological difficulties. Age, family functioning, parents' mental health problems, and their HRQoL did not contribute to the model.

Table 7. Predictors of child–parent disagreement on HRQoL (KIDSCREEN-10) in children and adolescents aged 8–18 years.

Fixed Effects	b	*SE*
Intercept	3.84 *	1.88
Child-related predictors		
Child psychopathology (CBCL 4-18, raw score)	−0.05 *	0.02
Female	−3.88 **	1.21
Age (years)	0.78	0.63
Age by gender-identity	−0.42	0.42

Table 7. *Cont.*

Fixed Effects	b	*SE*
Family-related predictors		
Family functioning (FB-A, raw score)	−0.05	0.04
Parental health-related quality of life (EQ-5D, raw score)	5.37	3.16
Parental psychopathology (BSI, raw score)	0.98	1.13

Note. n = 124, F = 5.25. df = 7/116. Model fit: adjusted R^2 = 19.5%. b = unstandardized coefficient *SE* = standard error, CI = confidence interval; all calculations were based on raw data and analyzed with a linear mixed model; all metric predictors were mean-centered; for measures, see text (Measures). * $p < 0.05$; ** $p < 0.01$.

4. Discussion

We aimed at analyzing the impact of various risk and protective factors on HRQoL in COPMI and at examining the magnitude, direction, and prediction of child–parent (dis)agreement. As expected, both parents and children reported considerable lower global and specific HRQoL than the reference population, although ratings still indicated medium life satisfaction [34]. Parents reported lower child HRQoL than their children on most HRQoL domains. Physical and psychological well-being were the most impaired aspects of HRQoL from both perspectives. In general, these results are in line with prior research confirming that HRQoL of COPMI is underreported by parents and lower than in the general population [4–8,48]. More pronounced impairments in psychological and physical aspects of HRQoL are common findings in previous studies too [8,29–32]. The results show that parental mental illness impairs many facets of HRQoL in children and adolescents. To prevent adverse outcomes in those children and to improve the children's resilience, interventions should target risk and protective factors of HRQoL in COPMI. To identify those, we analyzed the impact of various predictors of the children's life satisfaction. Overall, results were in line with our expectations. The most influential risk and protective predictors were child and parental psychopathology, social support, and the child's age. Of those, only social support was associated with higher HRQoL. The magnitude and the direction of the significant effects are consistent with other research [24,27,28,42,43,45,77–79]. The child's gender-identity, the interaction between the child's age and gender-identity, family functioning, and parental coping did not contribute significantly to the model, although the direction of the effects was in line with previous research [45]. Future research may evaluate whether these findings relate to overlap between predictors, the measurement instruments, sample characteristics, or whether their influence on HRQoL is lower as indicated by previous research [24,34–36,45]. The results imply that clinical interventions for COPMI should primarily focus on the improvement of psychological health of both children and parents, and on the increase of the children's supportive network (e.g., relatives, peers, professionals). Although the individual needs are diverse, research indicates that most children and adolescents prioritize learning more about their parent's mental illness, about ways to cope with it, and confidential support that is easy to access [80].

Mental health problems may affect parents' judgments regarding their children's HRQoL [10]. As parents are sometimes asked to make clinical decisions for their children, it is important to investigate the extent of child–parent agreement and to find probable explanations for disagreement. Consistent with our assumptions, reliability of interrater agreement between family members was fair for most global and specific aspects of HRQoL. It was slightly lower than in a study validating the proxy-version of the KIDSCREEN-27 in the general population (ICC = 0.44–0.61) [34]. However, this is in line with studies that have linked parental stress and mental health problems to higher informant discrepancies in the assessment of psychopathology and HRQoL [28,50,59,60,81]. The highest agreement was found for HRQoL relating to the school environment and the child's physical well-being. Family members disagreed most on the child's social relationships with peers and friends. Parents make more accurate proxy-ratings for observable aspects of behavior or for aspects like school environment for which they can rely on external sources (e.g., teachers' reports, grades) [45,82]. The quality of relationships with peers and the perceived social support by children are often outside the parents' visibility, especially during adolescence [49,61]. Social support and peers were also the subscale with the lowest agreement (ICC = 0.44) in the study validating the proxy-version of the KIDSCREEN-27 in the general population [34]. The most influential predictors of child–parent (dis)agreement on HRQoL in COPMI were mental health problems in children and the children's gender-identity. They explained 19.5% of the variance in the dependent variable. The difference between child–parent reports was lower when children were male and had emotional and behavioral difficulties. Overall, results are in line with other studies that identified similar predictors of (dis)agreement [45,49,50,57]. It has been suggested that there may be more child–parent agreement in children with mental health problems, and that the parent's perspective can provide additional valuable information on HRQoL in these situations [54]. The child's age, family functioning, parental psychopathology, and parental HRQoL did not contribute to the model, maybe because differences between child–parent ratings were too small to find significant effects. Although controversial results exist regarding effects of age [54,56], research has consistently demonstrated that highly functional families show higher child–parent agreement [57,58], and that the parent's mental health [10,59,60,83] and HRQoL [11] affect the proxy-ratings of their child's HRQoL. Differences in child–parent reports regarding the children's HRQoL have to be anticipated and regarded as valuable information in clinical and research contexts. Parents' perceptions may be influenced by their psychiatric symptoms, concerns, and by the burden of care-giving [52]. Moreover, children and parents may experience different situations and vary in their understanding of HRQoL, indicating the need to obtain information from multiple informants if possible [52].

This study had several limitations. Because all predictors and outcome variables were simultaneously assessed in this cross-sectional study, no temporal relationship between exposure and the outcome can be made. Longitudinal data are needed to make causal inferences. As with any regression analysis, support for the model predicting HRQoL in COPMI does not necessarily mean that the results can be generalized to other populations. The generalizability of the results to the population as a whole may further be limited due to the convenience sampling method. Results may be biased due to the reasons why volunteering participants chose to take part in the CHIMPS family intervention and others did not. Furthermore, no information was available on socioeconomic status and the children's physical condition. The latter may be a relevant predictor for physical aspects of HRQoL. Although we measured parents' perceived burden of symptoms, we did not differentiate between psychiatric diagnoses, symptom frequency, chronicity, prognosis, and duration of mental illness. Future studies may include these predictors to explain more variance in child HRQoL and to examine the model fit with regard to different psychopathologies.

5. Conclusions

Our findings suggest that HRQoL is impaired in COPMI. Interventions should concentrate on the children's psychological and physical well-being, as these seem to be the most impaired facets. To improve these domains of children's HRQoL, interventions should focus on the whole family. They may target the parental psychopathology with psychological interventions or provide social support for the children, as these aspects appear to be closely related to the children's HRQoL. Offering peer support groups may be one of many options to promote resilience and wellbeing in affected children by fostering psychoeducation, coping skills, and mutual support. Physical HRQoL in COPMI may be improved by cognitive interventions like mindfulness training and relaxation techniques. The disagreement found between children and parents on some aspects of the children's HRQoL emphasizes the need to obtain both self- and proxy-reports, whenever possible. Children should be provided the opportunity to describe their subjective view, especially when it comes to HRQoL aspects that are less observable from the outside, such as psychological well-being and social relationships with peers. Parent proxy-reports may be particularly useful when children are unable to self-report due to severe cognitive deficits or a young age, as well as when children tend to overreport high HRQoL to protect their parents. Research should continue to explore the direction and magnitude of child–parent agreement on HRQoL measures, and investigate reasons for disagreement. Results may aid clinicians to decide which HRQoL instrument is appropriate for a given sample, and in which contexts children's self and parents' proxy reports show high deviations.

Author Contributions: Conceptualization, A.R.; methodology, C.B., A.D., and K.W.; formal analysis, A.R.; original draft preparation, A.R.; writing—review and editing, A.R., C.B., and A.D.; visualization, A.R.; project administration, B.A. and S.W.-G.; funding acquisition, S.W.-G. All authors have read and agreed to the published version of the manuscript.

Funding: This research was funded by the Federal Ministry of Education and Research, grant number 01GY1337.

Institutional Review Board Statement: The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Ethics Committee of the regional Medical Association (Hamburg, Germany) under the number PV4744, 05.08.2014).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: Data available in a publicly accessible repository.

Acknowledgments: We thank the CHIMPS study group for providing the opportunity to evaluate the data. Members of the CHIMPS study group are: Wiegand-Grefe, Martin Lambert, Reinhold Kilian, Bonnie Adema, Karl Wegscheider, Anne Daubmann, Klaus-Thomas Kronmüller, Kai von Klitzing, Sibylle Winter, Kurt Albermann, Doris Mallmann, Christine Norra, and Mareike Busmann. We are grateful to all participants who gave their time and were willing to participate in this study.

Conflicts of Interest: The authors declare no conflict of interest. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript, or in the decision to publish the results.

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Own Contribution

Alina Radicke was responsible for the conceptualization of the research objectives and hypotheses, literature review, formal analyses, and interpretation of all research objectives as well as for writing this dissertation. The data was provided by the CHIMPS study group (‘Implementation and evaluation of a family-based intervention program for children and adolescents of parents with mental illness: a randomized controlled multicenter study’) with Prof. Dr. Wiegand-Grefe being the principal researcher. Alina Radicke was responsible for a part of the data curation.

Acknowledgements

There are a number of people without whom this thesis might not have been originated and finished, and to whom I am very grateful.

First, I would like to thank my primary supervisor Prof. Dr. Silke Wiegand-Grefe for her trust and support during the time of my PhD studies. She has always encouraged me to expand my scientific knowledge and skills by visiting scientific conferences and workshops as well as to expand my scientific network. Moreover, I thank Prof. Dr. Silke Wiegand-Grefe along with the CHIMPS study group (‘Implementation and evaluation of a family-based intervention program for children and adolescents of parents with mental illness: a randomized controlled multicenter study’) for providing the opportunity to evaluate the data. Members of the CHIMPS study group are Prof. Dr. Wiegand-Grefe (principal researcher), Prof. Dr. Martin Lambert, Prof. Dr. Reinhold Kilian, Dr. Bonnie Adema, Prof. Dr. Karl Wegscheider, Anne Daubmann, Prof. Dr. med. Klaus-Thomas Kronmüller, Prof. Dr. med. Kai von Klitzing, Prof. Dr. med. Sibylle M. Winter, Dr. med. Kurt Albermann, Dr. med. Doris Mallmann, PD Dr. med. Christine Norra. I am grateful to all participants who gave their time and were willing to participate in this study.

I thank Prof. Dr. Michael Schulte-Markwort for his support and for sharing his clinical expertise and perspectives on participative child and adolescent psychiatry. I am also grateful to Prof. Dr. Steffen Moritz for his help and cooperation during my PhD studies.

I am very grateful to Dr. Claus Barkmann and Anne Daubmann for their methodological and mental support as well as for their exceptionally fast and constructive feedback.

Furthermore, I would like to thank my entire working group for many fruitful discussions, constructive feedbacks and support.

Finally, I would like to thank my family and friends for their love and encouragement.

Curriculum Vitae

Der Lebenslauf wurde aus datenschutzrechtlichen Gründen entfernt.

Declaration in Lieu of Oath/ Eidesstattliche Erklärung

Ich versichere ausdrücklich, dass ich die Arbeit selbstständig und ohne fremde Hilfe verfasst, andere als die von mir angegebenen Quellen und Hilfsmittel nicht benutzt und die aus den benutzten Werken wörtlich oder inhaltlich entnommenen Stellen einzeln kenntlich gemacht habe.

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Ich erkläre mich einverstanden, dass meine Dissertation vom Dekanat der Medizinischen Fakultät mit einer gängigen Software zur Erkennung von Plagiaten überprüft werden kann.

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