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# **Geschwister psychisch erkrankter Menschen**

Übersehen – überhört – übergangen  
in den Familien und im Versorgungssystem

Auszug

The graphic features three overlapping, curved lines in shades of orange and red. One line starts at the top left, curves down and then up to the right. Another line starts at the top left, curves down and then up to the right, overlapping the first. A third line starts at the top left, curves down and then up to the right, overlapping the other two. The lines are thick and have a slightly textured appearance. The background is a light green color, and there are orange horizontal bars at the top and bottom of the page.

## X.3 Originalzitate

Die im Text verwendeten wörtlichen Zitate aus der angelsächsischen Literatur wurden von den Autoren übersetzt.

Nachfolgend wurden für interessierte Leserinnen und Leser die Originalzitate zusammengestellt.

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Sibling Support (2020): „dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns“ .....	67

- Holl (2015): „What siblings would like parents and service providers to know“ ..... 67
- Schizophrenia.com (2020a): „Schizophrenia.com is an internet community dedicated to providing high quality information, support and education to the family members, caregivers and individuals whose lives have been impacted by schizophrenia. This web community was founded in memory of John Chiko, who suffered from schizophrenia. We are dedicated to improving the lives of all individuals and families suffering from schizophrenia, and in speeding the research progress towards a cure.“ ..... 68
- Marsh u. a. (1993a, S. 2): „that their experiences and needs are likely to differ significantly as a result of their roles and relationships within the family“ ..... 69
- Smith und Greenberg (2008, S. 57): „With deinstitutionalization, many individuals with mental illness turned to their families for support because of the absence of adequate community-based services. Even today, with the presence of a greater array of community services, family members, in particular parents, often step in to fill in the gaps in the service system. However, many of these parents are now in their retirement years. Thus, growing numbers of adults with schizophrenia will likely look to their siblings for support as their aging parents' capacity to provide care diminishes and ultimately ends.“ ..... 69
- MacCourt u. a. (2013): „National Guidelines for a comprehensive service system to support family caregivers of adults with mental health problems and illnesses“ ..... 71
- MacCourt u. a. (2013, S. 17): „Having a sibling with mental illness affects the relationships, roles and health of other siblings. Siblings who were consulted on this issue were asked to name their most important needs. They identified seeking satisfactory services for their ill relative, working through their feelings about the illness, skills for coping and receiving personal support. Their greatest concern (82 per cent of participants) was about who would take care of their ill sibling when their parents no longer could.“ ..... 71
- SiblingsAustralia (2017a, S. 1): „They should be seen as siblings first.“ ..... 72
- SiblingsAustralia (2017b): „If we go down the ‚young carer‘ path, we will miss many siblings.“ ..... 72
- Nechmad u. a. (2000, S. 3): „Case control studies were used to explain how some well siblings ‚escaped‘ the pathological family network.“ ..... 74
- López u. a. (2004, S. 429): „Thus, warmth was thought to be too complex and, as a result, dropped from the definition of EE. From 1972 to the present, the study of EE has focused primarily on risk factors, largely over-looking protective factors against relapse.“ ..... 78
- Friedrich u. a. (2008, S. 266): „These findings underscore the importance of assisting siblings in the development of strategies that will maintain relationships with the ill siblings and decrease stress.“ ..... 79
- Sanders u. a. (2014, S. 257): „Findings [...] suggest that the well siblings score higher on two roles, the Hero and Lost Child, and lower on the Mascot and Scapegoat roles relative to a comparison group [...]. Being a sibling caregiver emerged as a risk factor to assume certain dysfunctional roles in the family.“ ..... 79

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Settersten (2003, S. 38): „individual lives are intimately connected to the lives of others, and individual development is bound to and shaped by these ties.“ .....	95
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- Dodge (2011, S. 92): „It made me feel a bit like I pushed him to be somewhere where he wasn't ready to be. So that's why maybe I am, like, a little more measured in my offering him help.“ ..... 129
- Stålberg u. a. (2004, S. 450): „If I keep myself busy the whole time, I keep my mind on that, but if I stop ... then maybe I'll think about that and that might be difficult.“. 131
- Levi (1986, S. 128): „But this love of mine is ambivalent, close to fear and rejection: it is similar to the emotion we feel for someone we love, who is suffering and asks for help we cannot give.“ ..... 133
- Titelman (2006, S. 843): „He was unable to distance himself from Kafka's terrible *malaise*.“ ..... 133
- Titelman (1997, S. 322f.): „This inner battle [...] can also be described as a struggle over unconscious hate against someone loved and against someone who is already defeated.“ ..... 134
- Bojanowski u. a. (2016b, S. 101): „In summary, the subjective experience of the sibling relationships are warmhearted, close, and affectionate within the CS [clinical sample] [and] can be seen as a resource or reflecting healing potential. For all children, the sibling relationship holds a very prominent position [...] which could be even more amplified in the case of mentally burdened children and adolescents.“ ..... 136
- Symons (2003, S. 10): „I saw my brothers and sisters in the full light of their loyalty and love. They were all indicted as ‚schizophrenigenic‘ 28 years ago, but when this illness threatened to take me away from them, they rose to the challenge and held out their hands to me in the moments I otherwise would have drowned. [...] They have traveled this distance with me unafraid. They have made my life richer, funnier, and filled to overflowing as a sister, an aunt, and a friend. Without them, it would have been a dark and difficult journey. With them, we have walked this 30-year road out of darkness into daybreak.“ ..... 139
- Elbogen und Johnson (2009, S. 152): „with other variables such as substance abuse, environmental stressors, and history of violence“ ..... 140
- Gluck (2019): „he chose jail time over treatment“ ..... 140
- Gluck (2019): „a silver lining in the darkness of pain his parents, his brother, and his family went through.“ ..... 141
- Dyregrov u. a. (2005, S. 719): „We are only siblings. I think that is how we feel, because our parents are really suffering. I understand their dreadful situation, because they have lost their child. But I have lost my brother ...“ ..... 148
- Klaassen (2013, S. 748): „Why are we so used to the idea that we resemble how our parents look, but does it take longer to realize that psychoses could work that way just as well? Because if my brother and I have similar features in our appearance because we have the same parents, does that mean we have those things in common that come into play with a psychosis? Apparently so. Symptoms of depression, often coupled with psychoses, are represented higher among siblings with those who have (had) a psychosis, than with those that have no relatives

- with psychotic symptoms. Evidently, we are more alike than we would have thought.“ ..... 152
- Sin u. a. (2012, S. 56): „He’s split up with his girlfriend, and one of the reasons is that he doesn’t want children.“ ..... 158
- Lukens u. a. (2004, S. 491): „Most of the others had made an active decision to remain childless, which they attributed to a combined fear of a genetic link and the cumulative burden of coping with the brother or sister with mental illness.“ ..... 158
- Lukens u. a. (2004, S. 493): „I’m single now, but I decided I won’t have children because I can’t go through that whole thing again. So that’s kind of hard.“ ..... 158
- Sullivan u. a. (2018, S. 3): „We now know that these genetic effects are relatively small and non-deterministic: most people with a strong family history are not themselves affected. [...] Moreover, most psychiatric disorders do not ‚breed true‘. For example, the immediate relatives of people with schizophrenia have increased risks for schizophrenia but also for multiple other conditions (e.g., bipolar disorder, major depressive disorder (MDD), and autism). The diverse clinical manifestations and variable course observed for many common psychiatric disorders are consistent with complex and relatively small genetic effects. For adult-onset common psychiatric disorders in particular, development is often within normal limits, although there is often some impairment of higher components of cognition.“ ..... 160
- Sullivan u. a. (2003, S. 1187): „support a view of schizophrenia as a complex trait that results from both genetic and shared environmental etiological influences“ ..... 162
- Lewontin (2003, S. 30): „The contrast between genetic and environmental, between nature and nurture, is not a contrast between fixed and changeable. It is a fallacy of biological determinism to say that if differences are in the genes, no change can occur.“ ..... 166
- Hudson (2005, S. 16): „The current study reveals a remarkably strong and consistent negative correlation between socio-economic conditions and mental illness, one that supports the role of social causation in mental illness and cannot be accounted for by geographic or economic downward mobility. The statewide database used in this study leaves little doubt that, at least in Massachusetts, the poorer one’s socio-economic conditions are, the higher one’s risk is for mental disability and psychiatric hospitalization.“ ..... 168
- Owen und O’Donovan (2017, S. 232): „Thus, psychiatric, cognitive and motor phenotypes tend to occur in clinical populations because they share underlying etiological and pathogenic mechanisms, but the mix of outcomes in any individual case will reflect that individual’s particular genetic complement and environmental history.“ ..... 169
- Erzin u. a. (2021, S. 172): „Exposome consists of three overlapping categories: the general external, specific external, and internal. The general external domain encompasses factors such as urbanicity, social capital, and stress, whereas the specific external domain includes factors such as diet, smoking, infections, pollutants, and chemical exposures. The internal domain comprises endogenous factors such as gut microbiota, oxidative stress, and metabolism.“ ..... 170

- Morrison (1991, S. 124): „Molecular genetics has brought help for some of the rare genetic disorders; the more common and more complex examples may be next. With brain imaging and neurochemistry, there is real promise, this engaged optimist says; even within this ‚Decade of the Brain‘, we may untwist ‚the twisted molecules and thence [...] the twisted minds‘.“ ..... 170
- Haukka u. a. (2003, S. 463): „These findings indicate that the genetic basis of schizophrenia is still unresolved, and it seems that no simple evolutionary mechanism can explain the persistence of genes connected to schizophrenia in the population.“ ..... 171
- Kendler (2005, S. 1250): „The impact of individual genes on risk for psychiatric illness is small, often nonspecific, and embedded in causal pathways of stunning complexity.“ ..... 173
- Johnson u. a. (2017, S. 1): „No evidence that schizophrenia candidate genes are more associated with schizophrenia than non-candidate genes“ ..... 173
- Johnson u. a. (2017, S. 7): „which are not expected to harbor a disproportionate number of risk alleles for schizophrenia“ ..... 173
- Johnson u. a. (2017, S. 7): „enormous time, talent, and effort in candidate gene studies over the years. It has been estimated that at least 250 million USD have been invested in candidate gene studies in the 1990s and 2000s.“ ..... 174
- Sullivan (2017, S. 696): „If it disagrees with experiment it is wrong. In that simple statement is the key to science. It does not make any difference how beautiful your guess is. It does not make any difference how smart you are, who made the guess, or what his name is – if it disagrees with experiment it is wrong. That is all there is to it.“ ..... 174
- Sullivan (2017, S. 697): „The data suggest that candidate gene guessing should be retired. This is not a new statement, as candidate gene studies have been controversial for decades, but the case can now be made forcibly.“ ..... 174
- Sullivan u. a. (2018, S. 2): „The PGC has recently commenced a program of research designed to deliver ‚actionable‘ findings – genomic results that (a) reveal fundamental biology, (b) inform clinical practice, and (c) deliver new therapeutic targets.“ ..... 175
- O’Donovan (2015, S. 293): „continued donation of biological samples from individuals (almost half a million have done so already) and on the willingness of more researchers to contribute what is often their life’s work of data acquisition.“ ..... 175
- Weinberger (1987): „It is conceivable that schizophrenia is not a disease per se but a state of brain maturation with a particular pattern of emergent responses to experience, which, for various diverse and complex genetic and environmental reasons, 1 % of the world population manifests.“ ..... 175
- Sullivan u. a. (2019, S. 162): „few individuals with a psychiatric disorder have a single, deterministic genetic cause; rather, developing a psychiatric disorder is influenced by hundreds of different genetic variants, consistent with a polygenetic model.“ ..... 177

- Dell'Osso u. a. (2019, S. 180f.): „However, in the last decades increasing literature is suggesting that psychiatric disorders can be better conceptualized as a ‚neurodevelopmental continuum‘ (NC). According to this model, similar kinds of alterations, linked to neurodevelopment, may lead to several different functional outcomes and phenotypic expressions. Such different trajectories seem to be related to both specific genetic characteristics and possible environmental influences, as well as to the timing of expression in the lifespan. The NC is a theoretical framework supported by several empirical evidences in multiple fields of research. The conceptual core of the NC model is that an alteration in brain development, determined by the intertwined relationships between genetic and environmental factors, may constitute the common underpinning of many (eventually, all) mental disorders.  
Moreover, the NC theory also implies that psychiatric disorders could be placed along a gradient of decreasing neurodevelopmental impairment. A possible model for this gradient could be understood in these terms: ASD with strong cognitive deficits (Kanner's type); ASD without mild/no cognitive deficits (Asperger's type); ADHD; intellectual disabilities; schizophrenia; eating disorders; bipolar disorders; anxiety disorders; vulnerability to traumatic experiences.  
According to this hypothesis, the concept of ND should be rethought, in order to include also functional psychoses (schizophrenia and bipolar disorders), and to be considered as a predisposing factor which may open the way to the onset of several other disorders, such as eating or anxiety disorders, as well as featuring a higher vulnerability to traumatic experiences.“ ..... 178
- Broad Institute (2018): „to separate reliable signals from noise“ [...] „each genetic variant only contributes a tiny percentage of the risk for developing a given disorder.“ ..... 179
- Broad Institute (2018): „The tradition of drawing these sharp lines when patients are diagnosed probably doesn't follow the reality, where mechanisms in the brain might cause overlapping symptoms.“ ..... 179
- Singh u. a. (2016, S. 571): „Combining these data with previous common variant evidence, we suggest that epigenetic dysregulation [...] is an important mechanism in the pathogenesis of schizophrenia.“ ..... 187
- Geburtig-Chiocchetti u. a. (2019): „Conduct disorder (CD) is characterized by a repetitive and persistent pattern of behaviour in which the basic rights of others or major age-appropriate societal norms or rules are violated.“ ..... 189
- Geburtig-Chiocchetti u. a. (2019): „environmental risk factors i) exposure to aggression or ii) stress during pregnancy, iii) maternal smoking during gestation, iv) psychiatric risk score of parents, v) difficult family situation, vi) parental education and vii) trauma experience.“ ..... 190
- Geburtig-Chiocchetti u. a. (2019): „In summary, we show for the first time that the observed altered methylation is mediating the specific signatures of environmental factors and suggest that these may ultimately converge into long-lasting neurobiological changes associated with CD.“ ..... 190
- Hughes (2014, S. 22): „The roots of inheritance may extend beyond the genome, but the mechanisms remain a puzzle.“ ..... 199

- Hughes (2014, S. 24): „If the mechanism involves DNA methylation, histones or RNA, the field is likely to make great progress in the next few years. [...] But if it's something completely novel [...] maybe it will take decades to figure out.“ ..... 199
- Shoah Resource Center (2019): „proactively commemorate the lives and way of life lost during the Holocaust“ ..... 205
- Goldberg (2014): „By narrating her story, I have found my voice. It is helping all of us move forward.“ ..... 205
- Nir (2018): „Transgenerational transmission of Holocaust trauma and its expressions in literature“ ..... 205
- Nir (2018, S. 5): „A dominant characteristic of second-generation families is the ‚conspiracy of silence‘. [...] In many such families, there was an ‚unspoken agreement‘ not to discuss the traumatic events of the Holocaust, most often out of the desire to protect the children. Despite this, the children tended to perceive this silence as emotional distance, which affected the quality of the relationship between parents and children.“ ..... 206
- Reinstädler u. a. (2018, S. 7): „as a highly disconcerting form [...] of ‚not-knowing‘, that hides behind the non-rememberable, the invisible and unspeakable“ ..... 208
- Titelman (1991, S. 79): „Ideas of having exploited the ill sibling professionally [...] or having benefited from the sibling's illness (e.g., by receiving psychotherapy).“ ..... 214
- Marsh u. a. (1993a, S. 5): „I became a perfect child to spare my parents more grief.“ .. 239
- Marsh u. a. (1993a, S. 5): „I am a super achiever with a great big hole inside.“ ..... 239
- Sin u. a. (2012, S. 55): „I am old enough to understand, but you still want a certain amount of attention from your parents. I don't see Mum that often, and when I see her, it's working around my brother.“ ..... 244
- Marsh u. a. (1993a, S. 10f.): „It was hell living at home. My sister and I were abandoned emotionally for many years. I was so depressed and lonely. I even thought of suicide. My needs were never important. I was in counselling for many years.“ ..... 246
- Blasko (2008): „Coping resources and emotional neglect among individuals with a sibling with a mental illness“ ..... 246
- Blasko (2008, S. 9): „Having a sibling with a mental illness seems a risk factor for emotional neglect, but is not itself a risk factor for poor stress coping. The present study suggests that it is emotional neglect which is a risk factor for poor stress coping.“ ..... 246
- Marsh u. a. (1993a, S. 11): „As a child I tried desperately not to have a problem because our family had so many. So, I became perfectionistic, hid my fears and concerns and needs from everyone.“ ..... 253
- Lukens und Thorning (2011, S. 211): „My parents were just glad that I was ‚occupied‘ and out of the house. But I desperately wanted them to tell me ‚No‘. I didn't want to tell my mother that I needed her. [...] She didn't need another kid with problems.“ ..... 254

- SDQ Info (2020):** Strengths and Difficulties Questionnaire (SDQ): „A brief behavioural screening questionnaire about 3-16-year-olds. It exists in several versions to meet the needs of researchers, clinicians and educationalists.“ ..... 255
- Marsh u. a. (1993a, S. 8):** „I had a hard time moving away, felt guilty all the time. My mom still wants me to move home.“ ..... 263
- Marsh u. a. (1993a, S. 11):** „Learn to set limits, to say no, to live apart, and not feel guilty about it.“ ..... 263
- Strohm (2002, Geleitwort):** „Give sorrow words; the grief that does not speak knits up the overwrought heart and bids it break.“ ..... 270
- Holl, E. (2015):** „Parents and service providers should not make assumptions about responsibilities typically developing siblings may assume without a frank and open discussion. [...] Self-determination, after all, is for everyone — including brothers and sisters.“ ..... 273
- Mulder und Lines (2005, S. 12):** „He’s living with me because he wanted more independence from our parents.“ ..... 274
- NAMI (2016, S. 41):** „Studies have found that siblings are most likely to take over as primary caregivers when parents are no longer able to provide care. Unfortunately, although many parents report that they hope this will happen, they seldom have conversations with siblings of the care recipient in advance to ensure they are willing, and prepared, to assume this role.“ ..... 274
- Czpri (2004):** „The sibling study: How does having a sibling with a mental disorder affect the lives of college students“ ..... 275
- Czpri (2004, S. 26):** „about their sibling’s ability to care for themselves in the future, or about taking care of the sibling in the future themselves.“ ..... 275
- SiblingsAustralia (2016, S. 10):** „[They] run away, they wanted their own life; they did not want to be tagged and considered ‚carer in waiting‘ and completely disappeared from the family dynamic.“ ..... 275
- Dodge (2011, S. 116):** „that sibling caregiving differed from parental caregiving. Sibling support was sporadic, inconsistent, and less comprehensive than the care parents provided.“ ..... 278
- Leith u. a. (2018, S. 1197):** „I strive to find a balance between doing things for myself and doing things for my ill sibling.“ ..... 282
- Leith u. a. (2018, S. 1201):** „who were members of a support or advocacy group like NAMI showed significantly higher levels of balanced sibling-care priorities“ ..... 282
- Lukens und Thorning (2011, S. 197):** „perhaps because course of illness and impaired functioning can be more severe in men.“ ..... 286
- Meyer (2015, S. 6):** „When we were younger, my parents always allowed us to be our own person without the expectation that we would someday care for Johnny. As a result, I never felt pressured and as a natural result of my love for him, I ‚care‘ for him.“ ..... 289
- SiblingsAustralia (2016, S. 10):** „She is here I believe because I never applied pressure for her to support her sister. I refuse to tag her as ‚carer in waiting‘.“ ..... 290

- Avcoğlu u. a. (2019, S. 259): „Indirect coping is described as a healthy way of coping by escaping rather than focusing on the siblings’ illness and burden [...]. It involves engagement with outlets or activities, inside and outside of the home, that occupies time and attention, and that brings pleasure.“ ..... 331
- Avcoğlu u. a. (2019, S. 259): „Social support seems to be the most important factor for well-being. It has a main effect and also it moderates burden.“ ..... 331
- Lazarus und Folkman (1984, S. 141): „constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.“ ..... 335
- Kellermann (2008, S. 269): „experience [others] their heritage as a powerful legacy that gives them a sense of purpose and meaning in life“ ..... 342
- Braaten (2018): „early lessons in intolerance and even cruelty affected my world view and gave me a deep desire to work on behalf of those who cannot always speak for themselves.“ ..... 344
- Spiro und Spiro (2018): „Looking back, she sees she made choices very much connected to Pam’s fate. She became a psychiatrist.“ ..... 345
- Carnevale (1999): „Striving to recapture our previous life: The experience of families with critically ill children“ ..... 352
- Mulder und Lines (2005, S. 12): „Instead of just being a brother I’m doing more parenting on issues like what’s appropriate behavior.“ ..... 353
- Moorman (1994): „Am I my brother’s keeper? No, I’m my brother’s brother.“ ..... 353
- Judge (1994, S. 175): „So while siblings have a meaningful and positive role to play in their siblings capacity, there is potential for tension and conflict if, and when, this relationship is characterized by caregiving.“ ..... 354
- Griffiths und Sin (2013, S. 2): „There’s also a lot of inspiration and hope in terms of the great things that you share as a sibling with your brother or sister. We do have a great laugh [...], there’s a lot of positive things along with, you know, this wave of negative stuff which comes with it.“ ..... 354
- SiblingsAustralia (2016, S. 10): „to be siblings and friends“ ..... 354
- Marsh u. a. (1993a, S. 18): „Most important, it is essential to reach out to young siblings and children as early as possible: To acknowledge their anguish, to address their needs, and to empower them in coping with this catastrophic event.“ ..... 363
- Hall und Purdy (2000, S. 427): „condemns too many consumers and their families to outcomes far short of what is possible.“ ..... 363
- Hall und Purdy (2000, S. 427): „to dance around the thorniest and most controversial issues in severe mental illnesses – such as individuals with the most intractable forms of illness or the relatively infrequent but very real situations in which either consumers or family members are assaultive or abusive.“ ..... 364
- Barak u. a. (2005, S. 234): „Information about the illness can help in reducing the sense of anxiety and guilt, and somewhat alleviate the sense of shame and stigma.“ .... 368
- Horwitz u. a. (1995, S. 138): „policy of community care for the seriously mentally ill [which] increases the caregiving duties and resulting burden on families.“ ..... 371

[Avcıoğlu u. a. \(2019, S. 258\)](#): „Thus, the perception of mother’s overprotection by the well siblings may have rendered feelings of being accepted and cared for despite the problems posed by the ill sibling.“ ..... 372

[Karancı und İnandılar \(2002, S. 86\)](#): „it may be likely that in highly traditional cultural contexts the patients expect their relatives to be distressed and protective and may interpret these as signs of caring and, therefore, lack of emotional over-involvement may in itself be also stressful for the patient“ ..... 372

[López u. a. \(2004, S. 428\)](#): „The data also indicated that for Mexican Americans, family warmth is a significant protective factor.“ ..... 372

[Lukens und Thorning \(2011, S. 204\)](#): „the distinct issues and concerns for the siblings became increasingly apparent“ ..... 380

[Hartling u. a. \(2014, S. 12\)](#): „Methodological rigour is required in future research.“ ..... 382

[Pitman \(2004, S. 388\)](#): „difficult for workers to use an evidence-based approach when trying to meet the needs of these children unless this information is described.“ 383

[Roberts u. a. \(2016, S. 2063\)](#): „Poorer emotional and behavioural functioning among participants and symptom severity of the child with special needs were associated with greater intervention effects.“ ..... 383

[Giallo u. a. \(2008, S. 86\)](#): „supporting them to strengthening family functioning, may be just as important as direct support to siblings“ ..... 383

[Lobato und Kao \(2002, S. 715\)](#): „because they wanted their well children to be able to meet and talk to peers with similar family circumstances“ ..... 384

[Riebschleger \(1991, S. 94\)](#): „mixed messages from the mental health system“ [...] „inclusion of siblings“ [...] „clear communication, [...] and, most of all, effective client intervention“ ..... 388