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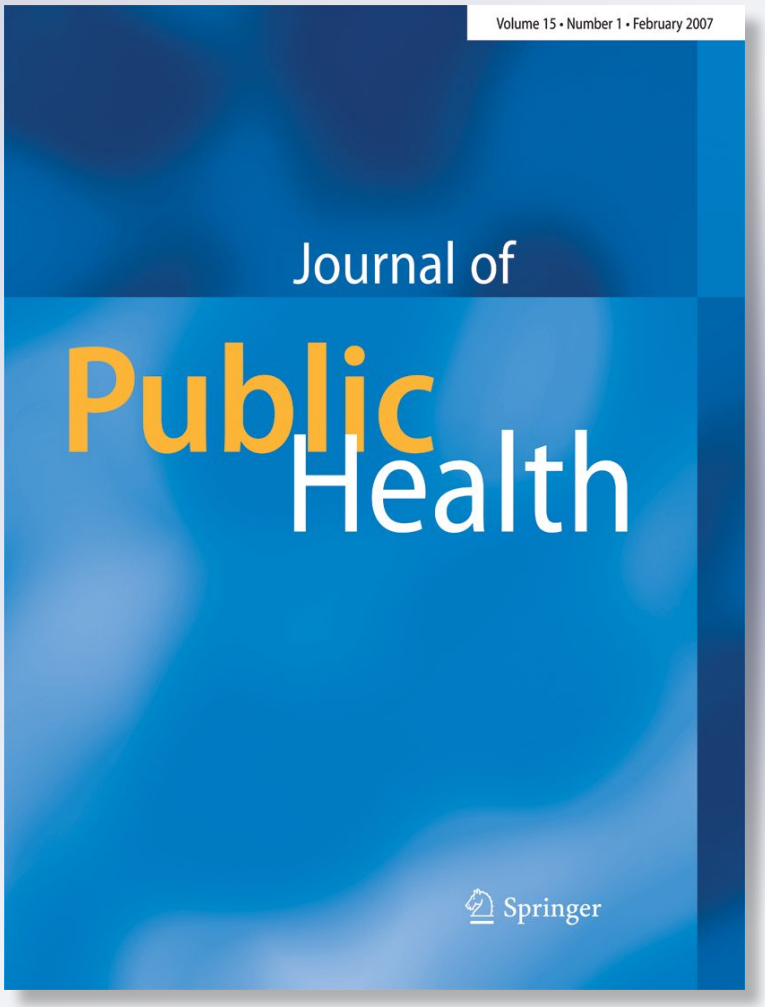

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ORIGINAL ARTICLE

Primary prevention for children of mentally ill parents: the *Kanu*-program

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Abstract
Aim The objective of the study is to develop, implement and evaluate a program of primary prevention for children of mentally ill parents. The main aim of the program is to reduce the burden on children and to improve their skills.
Subject and methods Study findings lead to the assumption that children of mentally ill parents are at a higher risk of developing mental disorders and behavioural problems themselves (Niemi et al. in Br J Psychiatry 186:108–114, 2005; Nomura et al. in J Am Acad Child Adolesc Psychiatr 41:402–409, 2002; Beardslee et al. in J Am Acad Child Adolesc Psychiatr 37:1134–1141, 1998; Lieb et al. in Arch Gen Psychiatry 59:365–374, 2002). Although there is a high need for prevention targeting this high-risk population, evidence-based preventive programs for children of mentally ill parents hardly exist (Foster et al. in Contemp Nurse 1–2:67–81, 2005; Heitmann and Bauer in Zeitschrift Pflegewissenschaft psychische Gesundheit 1:5–16, 2007). Therefore a primary preventive program was developed and implemented as a part of adult psychiatric care.
Results The preventive program consists of five elements: (1) a family-focused communicative intervention in order to improve the children's comprehension of the parental mental disorder (Beardslee 2009; Wiegand-Grefe in Analyt Kinder-Jugendlichen-Psychotherapie 1:81–96, 2008); (2) a godparent for children in order to avoid children being admitted into foster care while the parents are receiving therapy as inpatients (Trepte 2008; Beckmann and Szylowicki 2008); (3) a parenting program that will improve parenting skills as well as parent–child communication (Kühn and Petkov 2005); (4) a group program for affected children whose aim is to improve the children's social and communicative skills (Hipp and Staets in Soz Psychiatr 3:27–30, 2003); and (5) a module for networking and training of professionals. The evaluation mainly addresses children's burden, the parent–child interaction, quality of life, children's self-esteem and self-efficacy.
Conclusion Adequate support according to the needs of children with mentally ill parents is still difficult to predict. Many of the preventive options and projects are regionally limited as well as time-limited. A transfer to a national standard care system is desirable, as in reality the options often are unstable because they are limited, financially insecure and non transparent.

Keywords Mentally ill parents · Primary prevention · Childhood · Adolescence · Developmental risks

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Background

Studies show the increased risk for children of mentally ill parents of developing mental disorders or behavioural problems as a part of their socialization process (Rutter and Quinton 1984; Downey and Coyne 1990). Based on studies concerning families, twins or adoption, it is known that the disorder-specific risk of children of mentally ill parents has considerably increased. For instance, children of parents who suffer from a schizophrenic disorder have a

lifetime prevalence for schizophrenia of 13%, whereas the general population has a risk of only 1% (Schosser et al. 2006). In addition, the risk for a non-specific disorder has particularly increased regarding adolescents, where approx. 60% of children and adolescents of mentally ill parents develop temporary or permanent mental disorders or behavioural problems themselves. These risk associations are particularly well documented by study findings for children of parents with an affective or schizophrenic disorder (Cummings and Davies 1994; Niemi et al. 2005). A multifactorial etiology is discussed regarding the increased transmission of mental disorders within families. In addition to a genetic predisposition, psychological and social burdens are assumed to be risk factors for the children's development. These risk factors include, e.g. parental hostility, violence and aggression, reduced affective expression, limited positive reactions towards the children and serious conflicts between the parents (Mattejat et al. 2000).

Stress in childhood socialization courses

Studies conducted from the children's perspective (Lenz 2005) refer to the important subjective socialization risks. During their parent's time as inpatients, children and adolescents are likely to develop fears of loss, and compulsory hospitalization can even cause trauma. Furthermore, the risk of developing mental disorders, which children are often aware of, can evoke anxiety. Insufficient or even lack of communication about the disease—so called tabooing—can be an additional risk factor in the children's development. Experienced stigma or even fear of stigma and a lack of age-appropriate explanatory models are leading motives for parents to conceal their disease from their children as well as from the family. In particular, younger children do not understand the disease-related parental behaviour or mood disturbances and subsequently develop their own sense of guilt as they assume they have caused their parents disease phenomena (Mattejat 2008; Lenz 2005).

Older children and adolescents, however, are frequently affected by a reversal of roles as they take over the respective tasks of the affected parents. They may have to manage the whole household as well as provide care for the whole family, especially their siblings. This phenomenon is also known as parentification. For the affected children, it often means that they are not able to pursue their own interests and neglect their own needs, which leads to premature adulthood (Mattejat 2008; Lenz 2005; Schnepp and Metzing 2005). A study by Lenz (2005) shows that during the parent's inpatient treatment, specific and systematic integration, information and advice to children and adolescents are mostly not given by the hospital staff. The professionals of the adult psychiatric care system hardly regard children of mentally ill parents as relatives with preventive support needs. The professional support systems (child and adolescent psychiatry, youth welfare services) usually pay no attention to children of mentally ill parents until they have already developed mental disorders such as behavioural problems or if parents show deficits in their parenting abilities.

Need for evidence-based primary prevention

Despite the high epidemiological relevance (Lieb et al. 2002), there is still a lack of evidence-based primary prevention programs for children of mentally ill parents (Foster et al. 2005). Beyond local limited offers and projects (Hipp and Staets 2003), up to now there has been no primary preventive programs for children of mentally ill parents that take place within the routine care of adult psychiatry or youth welfare services. Also, there are few international studies that report on evaluated preventive approaches or scientifically accompanied preventive programs. Only Beardslee et al. (2003) conducted a few studies by developing and evaluating a preventive program for children and adolescents of parents suffering from affective disorders. These studies show a significant decline of risk factors by the affected children as well as enhanced protective factors. The authors found significant and, in the course of the prevention program, steadily improving behaviour by the parents as well as improved attitudes towards their children. The children in this study showed a higher level of understanding towards the parental mental disorder, while changes induced by the intervention were correlated positively between parents and children.

Objective and methodology

Regarding the *Kanu*-project, a primary preventive program has been developed which is currently being applied and evaluated in terms of its effectiveness. The study, which began in October 2008 and will be finished in March 2012, is supported by the German Federal Ministry of Education and Research (BMBF) in the context of the Federal Program for Primary Prevention Research. In order to improve the accessibility of the target group, the program was applied in clinical adult psychiatric care, which was an attempt to resolve the prevention dilemma that is well known in the target group (Bauer 2005). In the Department of Psychiatry and Psychotherapy Bielefeld Bethel, the prevention program was applied in the experimental group, while a control group was recruited from the mental

institution LWL-Klinik Gütersloh.[1] The primary target group of the program are children and adolescents aged between 6 and 14 who do not suffer from mental disorders or behavioural problems yet, and whose parents suffer from schizophrenia or affective disorders. The modular prevention program was developed based on (1) a national and international literature review; (2) qualitative interviews that were conducted in order to assess the family's problems and illness-related burden, as well as the needs for support of the affected parents and their children (Heitmann et al. 2010); (3) the conclusions of expert workshops conducted to obtain valid information from already existing offers and services for children with mentally ill parents (e.g. Wiegand-Grefe 2008; Staets and Hipp 2005). The modular concept was developed based on these findings in coordination with the Department of Psychiatry and Psychotherapy Bielefeld Bethel to assure practical accessibility. Furthermore, program development was supervised by former psychiatric patients.

Evaluation design

The present study evaluates the impact of the preventive interventions with regard to the level of psychological distress of the affected children. Furthermore, it aims at evaluating its impact on parenting skills of the affected parents as well as on family conditions and the networking skills of children and adolescents. Further aims of the evaluation are to assess changes in children's self-esteem, in children's regulation of emotions, in their quality of life and well-being such as children's ability of coping with stress. The evaluation was applied as a pre-post-design with a 6-month follow-up. The intervention takes place at the Department of Psychiatry and Psychotherapy Bielefeld Bethel and a control group was recruited in the LWL-Klinik Gütersloh, a comparable mental institution.

Subject of the primary preventive program

The program consists of five modules: parent, child and family talks, godparents, parenting training, a group program for children and adolescents and a module for networking and training of professionals.

Parent, child and family talks

This module focuses on the burdens of the affected children and parents that result from the phenomenon of illness tabooing. The aim of parent, child and family talks is to inform and educate parents with regard to their mental disorder and to provide an age-appropriate psychological education for their children. This element is based on the program already evaluated by Beardslee et al. (2003), Beardslee (2009), which was also applied and evaluated in a modified form in the University Hospital Hamburg Eppendorf (Wiegand-Grefe 2008; Wiegand-Grefe and Pollak 2006). This module is offered to all affected families. The parent, child and family talks aim at the detabooization of the parental illness within the family, thus reducing the problem of guilt felt by the children. The family's understanding as well as solutions to problems related to the mental disorder should be improved, which is the reason why the parents are instructed to explain their disease in an appropriate way to their children and to keep the channels of conversation open to their children. Another aim is to sensitize parents to the needs and feelings of their children. Furthermore, the family talks focus on improved disease-coping skills within the family and, where appropriate, on overcoming social isolation. Additionally relationships outside the family that focus on the education of parents regarding risk and protective factors for children's development and compensation for the negative parenting experiences of the children are additional components of the parent, child and family talks. Furthermore, significant familial burdens such as hospitalization, job loss or change of residence are also a part of the talks. In addition, whenever necessary, all family members are informed about support options and talks regarding the strengths and weaknesses of the children and the opportunities to foster children's strengths are given as options. The parent, child and family talks are offered over a period of 6 months and are structured as follows: (1) talks with the affected parent and, if applicable, the partner that also includes two to three parents or a couple; (2) a private talk with each child; and (3) talks including three families in which all family members participate (see also Wiegand-Grefe 2008).

Godparenting

Mentally ill parents sometimes have difficulties maintaining a steady relationship with their children or providing a supportive family framework such as conducting common familial activities or ensuring their children's social contacts. Godparenting is offered as a possibility for providing children with a continuous caregiver outside the family when needed, which could ensure constant and long-term support even when parents are receiving treatment as inpatients. The need for a godparent would be assessed during the parent, child and family talks (e.g. social isolation of the family). One objective of godparenting is to provide a sense of normality and orientation for the

[1] Both are clinical settings of the adult psychiatric care system that are regionally located in the German Federal State North-Rhine Westfalia.

affected children, as the parent-child relationship is insecure in some families. Godparent/child relationships that are already established are often implicitly based on findings from research studies which have shown that social support from a person outside the family can be a protective factor in the children's development process (Werner and Smith 1982; Trepte 2008). Without godparenting, children from families with poor social networks are particularly at risk at being removed from the family into foster care in the case of parental inpatient treatment.

These two basic problems are usually the focus of already existing godparenting situations for children of mentally ill parents in Germany. Another objective of the godparenting module therefore is to avoid the admission of the children into foster care in case of the parent's inpatient treatment, which is usually a significant burden. This module was developed in cooperation with the Child Protection Agency Bielefeld, which has already had experience with a godparenting model in the context of a program that focuses on the prevention of neglect and maltreatment in early childhood. The agency is in particular responsible for the recruitment and selection of interested volunteers and training the godparents for their role. Furthermore, the continuous monitoring and consulting of the godparents, the initiation of contact between the godparents and the affected families and the on-going support of the godparents are also part of the tasks of the agency. The staff of the agency arranges binding agreements regarding the structure of the godparenting model for each individual case and furthermore documents the course of each case. Trained employees of the Department of Psychiatry and Psychotherapy Bethel are contact persons for the godparents in case of psychiatric issues. The godparents support the children on a regular long-term basis in their everyday life, e.g. for leisure times or for school-related issues. They support the children and adolescents usually twice a week for several hours in order to establish a close relationship. If in the course of godparenting when family crises occur (e.g. when the parents receive inpatient treatment), families may need additional support. In these cases the affected children can be temporarily admitted in the household of the godparent. Thus the admission of the children into foster care can be avoided and the parent's inpatient treatment can be assured, since it is known that many parents do not seek treatment or seek treatment too late or cancel it prematurely (Schmidt et al. 2008) because of their concern about the children's care.

Kanu-parent training

The *Kanu*-parent training is based on the well-established parent training program STEP (systematic training for effective parenting; Kühn and Petkov 2005). The *Kanu*-parent training aims at strengthening parents in their educational roles and improving their relationship with their children, which also includes improving the parent's communication skills as well as reducing psychological crises. The group program addresses the affected parent and, where applicable, a partner or another important person of the affected parent. By involving the partner or another important person, a competent alliance between the affected parent and the other person will be sought. The *Kanu*-parent training takes place within the Department of Psychiatry and Psychotherapy Bielefeld Bethel and is offered weekly over a period of 10 weeks. The program is geared to show the parents how their style of education influences their children and how they can support their children in a positive manner; furthermore, parents learn to recognize the essential inappropriate behaviour of their children and how to make positive use of it. Another component of the training is to reflect to the parent in which way their values and beliefs can influence the children's behaviour. The importance of encouragement for the development of children's self-confidence is part of the training as well as appreciative and helpful communication with the children. In addition, it is shown how to engage with children to gain their cooperation and assistance. Moreover, the program points out opportunities to offer limits to children in a friendly but consistent manner and demonstrates how children are able to learn from the consequences of their actions. The program concludes with a family conference (Kühn and Petkov 2005).

Kanu- group program for children and adolescents

Another module of the *Kanu*-project is a group program for children of mentally ill parents to improve the children's life skills. The course focuses on normalization, dealing with emotions, stress and family crisis. This module is addressed in particular to children who are already affected to a considerable extent by parentification. In such a program they can benefit from a creative and playful environment that enhances the opportunity to be a child again. Part of the normalization is that children get in contact with other affected children and can learn that there are other children who share and understand their problems. In this way, there is an opportunity for emotional relief as children get in contact and have conversations with other children whose parents also suffer from a mental disorder. The promotion of self-reflection and self-esteem to offer space to children outside of the parental illness is also a component of this module. Along with this, the social skills of children and adolescents are encouraged in order to improve their capacity to deal with stigma and discrimination. The physical and creative activities of this module aim at promoting conversation with other affected children and

offering age-appropriate activities (Staets and Hipp 2005; Dierks 2001). Many children are already emotionally confused by the parent's cognitive, emotional and behavioural disturbances (Mattejat et al. 2000; Schone and Wagenblass 2002), which is why they are supplied with skills to foster emotional awareness and self-control. Based on already tested concepts (Wilms and Wilms 2004; Barrett et al. 2003), the children learn to be aware of the perception of their own and feelings as well as those of others. As a result of a lack of family illness communication, many children are burdened by feelings of guilt and the taboo of family problems that furthermore leads to an increasing isolation (Lenz 2005; Schone and Wagenblass 2002). As part of the group program, the strengthening of children's resilience by building self-confidence takes place. A theater-education component aims at improving children's ability to deal with stress and crisis situations. The group program is conducted weekly in homogenous age groups and consists of ten events.

Networking and training

In their study, Schone and Wagenblass (2002) identified existing cooperation barriers in the support system that avert effective prevention for children of mentally ill parents. A lack of knowledge in the youth welfare services as well as in the adult psychiatric care system about the life situation and possible risks of the affected children and a lack of knowledge about the opportunities in the respective support systems are all part of these cooperation barriers. The authors point out that an interdisciplinary perspective can mostly not be found, though it is deemed to be necessary, to refer to the approaches of the participating institutions and professionals. Therefore there is criticism that social support and opportunities of support from adult psychiatry and youth welfare services in general only refer to parts of the family system, which, at the very least, is also due to the fact that the financial channels are dissected and the communication between the involved professionals is insufficient. Therefore the authors ask the involved support services to come to an agreement about the opportunities and limits of the various institutions. These problems with the service interfaces are well known in the regional context of the project, which will be taken up in the last module of the *Kanu*-project and will be analysed there. The aim of this module is to improve the cooperation between the professionals from the youth welfare services and adult psychiatry via workshops, seminars and conferences. In the context of the development of the *Kanu*-prevention modules, it was already possible to draw on the expertise of the two areas and to initiate a discussion between them. The networking includes common conferences as well as the establishment of a work group on children of mentally ill parents in the PSAG (Psychosocial Working Group) Bielefeld. This work group also deals with the improvement of networking and the creation of transparency and rapid communication between the support systems.

Conclusion

Prevention services for children of mentally ill parents are often regionally grown and usually not reviewed by scientific criteria. However, a very impressive and diverse range of preventive opportunities already exists. The variety of programs and projects is a result, for example, of the different target groups which are addressed. Also noteworthy are the different levels to which prevention-oriented opportunities are attached; whereas some offers and projects focus on the behaviour of family members, others address the environment by improving the networking and collaboration of the involved care services. In this context the *Kanu*-project attempts to fill an existing support gap and to sensitize the public and especially the scientific community to the situation of children of mentally ill parents. Adequate support according to the needs of children with mentally ill parents is still difficult to predict. Many of the preventive options and projects are regionally limited as well as time-limited. A transfer to a national standard care system is desirable, as in reality the options often are unstable because they are limited, financially insecure and non transparent. Future challenges are, for instance, better accessibility of the affected families, the networking of the professional support systems and the sustainable financing of preventive offers. The recent experience of the *Kanu*-project as well as the experiences of programs which already existed before can indicate opportunities for improving the support of the affected families.

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Conflict of interest The authors declare that they have no conflict of interest.

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